

PHD

Understanding quality of life

investigating the effects of individualised feedback on wellbeing

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Award date:
2012

Awarding institution:
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**Understanding Quality of Life: Investigating the effects of
individualised feedback on wellbeing**

Alison Mary Llewellyn

A thesis submitted for the degree of Doctor of Philosophy
University of Bath

Department of Psychology

July 2012

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***“The real voyage of discovery consists not in seeking
new landscapes, but in having new eyes.”***

Marcel Proust (1871 – 1922)

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ACKNOWLEDGEMENTS

My utmost thanks go firstly to my supervisor, Professor Suzanne Skevington. I will be forever grateful to you for your tireless support and for your unswervingly insightful advice. You have been the key to my journey from undergraduate student to submitting my PhD and I hope we will continue to share our love of travel and green tea! Thanks are also due to so many colleagues along the way. To all the fellow students with whom I have shared this seemingly epic adventure, thank you for your companionship, the (sometimes obscure but always entertaining) conversation, and for always willing me to succeed. Particular thanks go to Dr Karen Evans, my “study buddy” and a true friend, but also to Dr Keely Gunson, Dr Ayana Sato, Dr Fiona Begen, Kelly Clifford, Kitty Chan, and the rest of the great guys and gals in the Tractor Shed – you know who you are! I am grateful to each of you and wish you all your individual triumphs in the future.

Thank you also to all those who have been so vital in enabling my research. From Professor Candy McCabe who helped set me off on this quest with such enthusiasm, to those wonderful organisations that have helped me recruit participants or arranged offices in which to conduct interviews, I am in your debt. But of course, special thanks must go to all those individuals who gave so generously of their time and energy in taking part in the research, I can truly say this PhD would not have been finished without you.

When I began a career in Human Resources so long ago, I would never have imagined returning to studying and being where I am today. To my Dad, and all those who have been part of this long journey, thank you for the riches you have given me in terms of friendship, encouragement, wisdom and energy. I am blessed to have such wonderful friends and family.

Finally, special thanks must go to my husband, Gareth, and to our children Rose and Alex. For supporting me in so many ways, for your endless patience and particularly for always believing in me, thank you so much.

This thesis is dedicated to my Mum, who would have been very proud.

ABSTRACT

Recent initiatives in healthcare have begun to take a person-centred approach to treatment and consultation. Quality of Life (QoL) measures have also developed, bringing a precision that enables their use with individuals. However, applications of QoL data have tended to focus on its use by care providers. This programme of research investigated whether QoL information, applied at an individual level, was associated with changes in people's perceptions of their wellbeing.

A unique protocol was developed for feeding back results from the WHOQOL-BREF and WHOQOL Importance instruments. A new graphical summary profile was generated as the core mechanism for individualised feedback. Two alternative approaches were developed: verbal guidance given by a facilitator while the participant viewed his or her graphical profile, and written instructions for inspecting the profile, to be followed by the participant when inspecting the profile independently. Initial methodological development work examined the feasibility, acceptability and face validity of these components. A "proof of principle" pilot study then investigated whether thinking about QoL, without feedback, led to effects in scores on measures of wellbeing. The main study ($N=129$) examined the effects of providing structured feedback on QoL (WHOQOL-BREF and Importance), mood (PANAS), health status (EQ-5D) and goal-oriented QoL (adapted GOSS). A follow-up study examined qualitative reflections on receiving feedback and the psychometric properties of the QoL measures were also investigated.

Findings showed no effects from merely thinking about QoL, but it was found that WHOQOL-BREF ratings of psychological health increased after receiving structured individualised feedback ($F(1,117) = 7.75, p < .05, \eta^2 = 0.62$). No differences were found relating to feedback administration (verbal guidance or written instructions). Qualitative data revealed participants' interest in QoL, and beliefs that their thinking about QoL had changed. Psychometric analyses confirmed the consistency, reliability, and validity of the WHOQOL instruments.

It was concluded that providing individualised feedback on subjective judgements of QoL was associated with positive changes in people's perceptions of their psychological

health, as measured by the WHOQOL-BREF. This approach has potential to be used within or outside healthcare settings and could be valuable in individual self-management and decision-making.

FREQUENTLY CITED ABBREVIATIONS

Analysis of variance	ANOVA
EuroQoL EQ-5D self-report questionnaire	EQ-5D
Factor analysis	FA
Functional Assessment of Cancer Therapy	FACT
Goal Oriented Subjective Status	GOSS
International classification of diseases	ICD
Multivariate analysis of variance	MANOVA
Quality of life-related goal orientation measure	GOSS-Q
Positive and Negative Affect Schedule	PANAS
Principal component analysis	PCA
Patient reported outcome measures	PROMs
Quality of life	QoL
Self-regulatory theory	SRT
Subjective wellbeing	SWB
Visual analogue scale	VAS
World Health Organisation	WHO
World Health Organisation Quality of Life	WHOQOL
World Health Organisation Quality of Life Assessment – Brief	WHOQOL-BREF

CHAPTER 1. INTRODUCTION

Recent years have seen a move in the UK towards the inclusion of the concept of wellbeing into governmental societal measures. In 2010 the Office for National Statistics initiated a debate on wellbeing and subsequently began to measure it nationally. Including wellbeing questions for the first time in its UK-wide census, it asked respondents to rate their satisfaction with life; the extent to which they thought what they did was worthwhile; and how happy and how anxious they were feeling “yesterday” (The Office for National Statistics, 2011). In defining wellbeing, the New Economics Foundation think tank more recently made a distinction between national wellbeing – “*the overall state of the nation in terms of environmental sustainability, social and economic factors*”, and human wellbeing – “*the extent to which people experience happiness and satisfaction, and are functioning well*” (New Economics Foundation, 2011, p. 4). The Department for Environment, Food and Rural Affairs also published the following definition of wellbeing: “*a positive physical, social and mental state; it is not just the absence of pain, discomfort and incapacity. It requires that basic needs are met, that individuals have a sense of purpose, and that they feel able to achieve important personal goals and participate in society. It is enhanced by conditions that include supportive personal relationships, strong and inclusive communities, good health, financial and personal security, rewarding employment, and a healthy and attractive environment.*” (Department for Environment Food and Rural Affairs, 2010, p. 106). It is becoming clear that the measurement of individualised wellbeing is starting to be a key consideration in the development of public policy. Indeed, Lord Layard (Layard, 2010) has asserted that every survey of individuals should include the assessment of well-being, in order to ensure that the policy makers can understand what really matters to people.

At the same time, there has been considerable effort to improve the care quality and efficiency of the UK health system. In recent years a range of patient reported outcome measures (PROMs) has been developed in order to improve patient involvement and to enhance appreciation of patient views, by capturing their perspectives on illness, health

and intervention effects and Quality of Life (QoL). The current economic imperative for the adoption of PROMs was established in Lord Darzi's NHS Next Stage Review Final Report (Department of Health, 2008), in which he stated that PROMs would be one of the quality measures upon which payments to NHS hospitals would be conditional. Consequently, since April 2009, all licensed providers of NHS unilateral hip and knee replacement services, groin hernia surgery and varicose vein surgery, have been required to routinely collect and report on a range of PROMs (Department of Health, 2009). Measures include generic and condition-specific measures of health status plus questions about the patient's living arrangements, whether they were helped to complete the questionnaire, whether they consider themselves to have a disability, and how they perceive their QoL. Demonstrating its future commitment to patient-centred measures, in July 2012 the Department of Health published a draft mandate in which it stated its intention to improve the information it collects about NHS services, including extending the breadth and quality of information collected using PROMs (Department of Health, 2012).

1.1 What is Quality of Life?

The expression "quality of life" is frequently used in many everyday contexts – indeed, via the media and in regular conversation it has become established in the public psyche. It is referred to just as readily in discussions about individuals' specific circumstances, as it is in debates about standards at societal or policy levels. QoL is a term used recurrently by politicians, economists, social workers and doctors alike, and is one that is often employed as a measure of the outcomes of public policy (Bowling, 2005b). Even within the realm of science, QoL has been asserted to be a unifying concept that brings together scientists from many different disciplines (Seed & Lloyd, 1997). Yet, it is a term which is poorly defined (Fayers & Machin, 2007). Indeed, it has been asserted that as many definitions exist as there are those who study QoL (Baker & Intagliata, 1982).

QoL can be considered in both macro (objective, societal) and micro (subjective, individual) terms and these categorisations include aspects such as education, living circumstances, employment, values, happiness, health and life satisfaction (Bowling, 2005b; Brown, Bowling, & Flynn, 2004). Objective QoL has been postulated to refer to material and social circumstances that can foster, or diminish, wellbeing; and subjective QoL to refer to relative assessments, consideration of life history, values and expectations (McAllister, 2005).

Taking a broad perspective, QoL can be thought of as a multidimensional construct within which different aspects interact (Brown et al., 2004). However, it has also been argued that it is possible to consider QoL as a unidimensional construct in terms of how people feel about their QoL as a whole, i.e. as a consequence of a generalised assessment across a range of dimensions (Beckie & Hayduk, 1997). A widely accepted perspective is that of the World Health Organisation (WHO) who assert that QoL is “*a broad ranging concept, incorporating in a complex way individuals’ physical health, psychological state, level of independence, social relationships, personal beliefs and their relationships to salient features of the environment*” (The WHOQOL Group, 1995, p. 1405). One illustration of the complexity of the construction is presented when the complex interactions of objective and subjective judgements are considered. For instance, an individual can have positive feelings and judge themselves to be happy, yet at the same time acknowledging that they live in poverty or suffer poor physical health. Similarly it has been asserted that those in poor conditions frequently are satisfied, while privileged persons may be very dissatisfied (Noll, 2000). Bowling (2005b) suggested that, whether consciously or unconsciously, people adapt to changing circumstances in order to remain feeling positive about themselves. Further, the basis upon which QoL self-judgements are made are comparative (Fayers, Langston, Robertson, & Prism Trial Group, 2007; Felce & Perry, 1995). For example, a person with a health condition affecting their dexterity may identify the deleterious consequences of this on their daily activities, but feel that their QoL is still better than that of another whose disability affects their mobility and impacts their social activities. Such examples illustrate the importance of an individual’s frame of reference in his or her self-assessments of QoL. The complexity of QoL is also evident when one acknowledges that different parts of

QoL “*affect each other as well as the sum*” (Brown et al., 2004, p. 7). For example, physical health may affect a person’s ability to retain independence or to maintain friendships, and these factors may in turn impact emotional wellbeing.

Within this paradigm, a pragmatic and well established definition has been provided by the WHO. This definition conceptualises QoL as “*individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.*” (The WHOQOL Group, 1995, p. 1405). Rapley (2003) asserted that the strength of this definition lies in its comprehensiveness and consideration of the importance of cultural, social and environmental circumstances. Further, it clearly recognises that subjective QoL is a social construction, with different meanings for different people. In this context it is a person’s idiosyncratic perspective that is critical to understanding the meaning they attach to the construct. Whilst certain dimensions, such as physical functioning can also be measured objectively, what clearly matters most is the individual’s perception of themselves.

Many other definitions of QoL have drawn similar conclusions to those of the WHO. For example, a number of authors have concurred that QoL represents the gap between expectations and experience (Calman, 1984; Carr, Gibson, & Robinson, 2001). The premise of these “gap” theorists is that QoL corresponds to individuals’ appraisal of their current conditions compared with what they perceive to be possible or ideal (Velikova et al., 2008). What is clear so far is that QoL is generally accepted to be a complex and multidimensional construct (Brown et al., 2004). It can be affected by many factors including physical health, psychological states, social relationships, environment, spirituality and the ability to be independent.

1.1.1 Quantifying quality of life

Questioning the nature of QoL has been an enduring pursuit since the time of the Greek philosophers who asserted that having a good life was interwoven with the concept of happiness (Fayers & Machin, 2007). However, quantifying quality – seeking to identify numerical parameters to illustrate the relative levels of this quality – has been a more

recent endeavour. After the Depression of the 1930's, developed countries began to evaluate QoL in terms of external standards such as nutrition, housing and education. At the same time financial statistics such as economic growth or income per capita started to be applied as indications of QoL (Cella & Tulskey, 1993). However, the 1960's saw a shift away from fiscal concerns towards recognising the social aspects of QoL (Rapley, 2003). This evolution of the concept of QoL from net worth or extrinsic achievements to less tangible evaluations of happiness or satisfaction brought with it a challenge in terms of how to measure the construct of QoL reliably. No longer was quantification of income or possessions sufficient, subjective evaluations also became necessary. As A. Campbell (1976, p. 118) pointed out, "*quality of life lies in the experience of life*". Consequently, while some approaches still attempted to measure objective indicators such as place of residence, marital status and occupation, others began to consider more subjective measures of life satisfaction and wellbeing (Cella & Tulskey, 1993). Whereas traditional psychological models had been based on Maslow's (1954) hierarchy of human needs, modern approaches began to centre around social expectations and the gap between experience and expectations (Calman, 1984). Social and psychological indicators began to be applied at the level of individual welfare (Felce & Perry, 1995; Velikova et al., 2004) and some researchers also began to take a phenomenological approach, focussing on individual's perceptions of themselves and their circumstances. (Joyce, McGee, & O'Boyle, 1999).

From this historical basis, a broad range of modern instruments has been developed, each of which attempts to measure different dimensions of the construct of QoL. However measures differ in the extent to which they are person-centred (Greenhalgh, Long, & Flynn, 2005). Some instruments, such as the SEIQoL (O'Boyle et al., 1993), are broad in terms of allowing individuals to specify what matters, or is important to them. In others, domains of QoL are defined, but participants have contributed to item content, for example the EORTC QLQ-C30 (Aaronson et al., 1993). At the clinical end of the range are measures that comprise such factors as self-reports of health status rather than individual perspectives on life experiences, for example the SF-36 (Ware, 1993)

More recently, discussions about applying outcome measures for use with individuals has been encouraged by the development of high calibre person-centred QoL instruments (Skevington & McCrate, 2012). Using QoL data in this way demands greater precision and more stringent criteria than for measures assessing the QoL of groups. For example, it is asserted that such measures need to have been developed with the involvement and input of the people who might ultimately be asked to complete them (Skevington & McCrate, 2012). The WHOQOL is one such instrument that fulfils both the requirement for precision and user involvement in the development of the measure.

1.1.2 Development of the WHOQOL instruments

In the early 1990's the World Health Organisation set up a collaborative project to develop a cross-cultural measure of QoL for use in health and health care. The project included users from the outset, eliciting qualitative information from focus groups of community members, health professional and patients in 15 countries. These user-generated data were employed both in selecting QoL concepts for inclusion in the measure, and also users words and phrases were used in writing items and response scale labels. The information provided was subsequently integrated in order that concepts and language could be structured into a "universal" framework of QoL that could be applied cross-culturally (Skevington, Sartorius, & Amir, 2004). In seeking to provide an assessment instrument incorporating a range of dimensions, the WHOQOL Group began with 134 facets of QoL, clustered into seven domains. Questions were positively framed as much as possible, to avoid the problem-centred focus of many other QoL instruments. From this the items were distilled into 26 facets, clustered within 6 domains: physical health, psychological, independence, social relationships, environmental, and spirituality, religion and personal beliefs as well as an overall QoL and general health perception facet. Cross cultural survey data confirmed the holistic selection of internationally approved facets of QoL and it has been determined that the WHOQOL has good semantic and conceptual equivalence between language versions (Bowden & Fox-Rushby, 2003).

1.1.3 *Measuring relative importance in quality of life*

Earlier it was established that QoL is a multi-dimensional construct. However, what has often not been considered is the relative importance of dimensions, not only between individuals, but also, at a person-centred level, across the profile of the different dimensions of one person's QoL. Yet understanding the importance of different aspects of QoL may have considerable benefit. For example, importance information in healthcare may be a valuable heuristic for prioritising those features of healthcare services that are particularly valued by patients. An exception to the lack of research was a UK single culture study in the early 1990's. In this study Bowling (1995b) asked 2000 participants to rank the more important aspects of their QoL and found the most frequently mentioned areas related to standard of living; relationships; health (of self and others) and social life. A handful of other studies have looked the importance of sexuality in comparison with other dimensions. For example Gott and Hinchliff (2003) found sex life was important to older adults with a current sexual partner. Others have found spirituality to be important to more important for people with a chronic illness than for people who are religious and healthy (da Rocha, 2011).

Despite these insightful findings, individual preferences relating to importance remain absent from many QoL measures and this has been asserted to be a fundamental limitation (Kind, 1996). Some QoL instruments assume that different aspects of QoL have equal importance (Skevington & O'Connell, 2004). Even where judgements about the relative importance of dimensions are made, it has been suggested this may be in the absence of any substantive information and that the judgements are often drawn "*implicitly, arbitrarily, and in an idiosyncratic way*" (R. M. Kaplan, Feeny, & Revicki, 1999, p. 136).

When the WHOQOL instruments were developed, importance items corresponding to facets of QoL were included alongside the original WHOQOL-100 core items. These have since been applied in a small number of studies cross-culturally (Molzahn, Kalfoss, Skevington, & Schick Makaroff, 2011; Molzahn, Skevington, Kalfoss, & Schick Makaroff, 2010; Saxena, Carlson, Billington, & Orley, 2001; Skevington & O'Connell, 2004). The psychometric properties of the importance measure have not been fully

studied in depth, but so far, results from these studies have suggested good internal consistency and reliability.

1.1.4 *Quality of life and wellbeing – are they the same?*

The terms QoL and wellbeing have often been used synonymously to describe shared concepts. For example, in one definition QoL was proposed simply as “subjective wellbeing” (SWB) (S. R. Cohen, Mount, & MacDonald, 1996, p. 753). Some authors argue that the two concepts are different, regarding SWB as a solely positive construct that encompasses emotions such as happiness, life satisfaction, morale, self-esteem and coherence and QoL as a bipolar construct, including both positive and negative aspects (Bowling, 2005a).

However other recent definitions take a less value-laden perspective. Diener (2006, p. 400) reported SWB to be “*an umbrella term for the different valuations people make regarding their lives, the events happening to them, their bodies and minds, and the circumstances in which they live*” making no reference to the relative positivity or negativity of those valuations. Similarly Felce and Perry (1995, p. 60) defined SWB as “*an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values*”. It has also been asserted that SWB is more than the absence of problems such as physical or illness or poor mental health and may also include dimensions such as self-knowledge or spirituality that relate to meaning of life (Phillips, 2006). These definitions of SWB are very similar to those of QoL, and particularly to the WHOQOL definition of QoL discussed earlier (The WHOQOL Group, 1995). Indeed the latter has been asserted to display considerable correspondence with Diener’s (2006) definition of SWB, particularly in its inclusion of life circumstances and individual values, and the two terms therefore determined to be virtually synonymous (Camfield & Skevington, 2008). That the two idioms have been found to be analogous is reflected in their use in the present programme of research.

1.2 Quality of Life and Healthcare: Patient Reported Outcomes

Following the move towards the adoption of PROMs, as mentioned earlier in this chapter, their regular use has been postulated to be effective in both improving the processes and outcomes of care. For example, a number of controlled trials have demonstrated that using PROMs may be an effective method of enhancing two-way communication in patient-physician relationships (Detmar, Muller, Schornagel, Wever, & Aaronson, 2002; Taenzer et al., 2000; Velikova et al., 2004). It has also been suggested that support for their use often stems from the role they play in changing how health problems are perceived and managed both by patients and clinicians (Marshall, Haywood, & Fitzpatrick, 2006). Indeed, in the context of chronic illness, Marshall et al. (2006) suggested that the potential value of PROMs lies especially in facilitating shared identification of goals and priorities between patients and health professionals in the face of complex and evolving problems. As a PROM, this further indicates a potential role for QoL information in helping to individualise treatments and in enabling shared decision making.

Alongside the introduction of PROMs, an increasing recognition of the wider ranging effects, for patients, of life events has already led healthcare researchers to investigate more holistic concepts like QoL, as well as the physical effects of life changes. In healthcare, the move towards biopsychosocial models has contributed to growing interest in measurement of the QoL of patients and to the application of this data in settings such as clinical practice (Velikova et al., 2004). Recent studies report that QoL information is valued by health professionals (Baars, Pal, Koopman, & Wit, 2004; Skevington, Day, Chisholm, & Trueman, 2005) and many investigations into the use of QoL data have examined the effectiveness and utility of this information from the viewpoint of those providing support or care (Greenhalgh et al., 2005; Gutteling et al., 2008; Hilarius, Kloeg, Gundy, & Aaronson, 2008; Velikova et al., 2008; Velikova et al., 2004; Velikova et al., 2010). Where there remains considerable scope for research, is into the development of interventions which use QoL information to enhance individuals' understanding of their own lives, and in a way that promotes their overall wellbeing. Although an obvious application is within healthcare, this does not imply

that such an approach is inappropriate elsewhere. Although this assertion is, as yet, untested, it may prove to be just as relevant for those facing significant challenges or changes in other aspects of life, for example: redundancy changing job role, bereavement, relocation, and other similar life events.

Having defined QoL and established the current UK political and healthcare context in which QoL measures can be applied, the next chapter will examine the theoretical framework for the present programme of research.

CHAPTER 2. THEORY AND RATIONALE

The previous chapter considered the definition of QoL and discussed how this construct has been measured and researched in healthcare contexts. The current chapter will set out the theoretical framework in which the present programme of research is grounded and will elucidate the rationale for the work. The aims and phases of the research programme will be outlined.

The Medical Research Council (MRC) is a UK body which works with the Department of Health and National Health Service (NHS) with the aim of improving health through research. Since 2000, the MRC has provided advice on the development, evaluation and implementation of complex interventions to improve health (Medical Research Council, 2000, 2008). The new MRC guidance clearly states that the development of an intervention requires the identification of a coherent theoretical basis and that suggests that this is more likely to result in an effective intervention than a purely empirical or pragmatic approach. Similarly, Michie, Johnston, Francis, Hardeman and Eccles (2008) endorse the value of theory, suggesting that interventions based in theory are better able to be understood in terms of the effectiveness of their various elements. Furthermore, they assert that such interventions can, in turn, contribute to the development of better theories in a range of contexts and populations and in regard to an array of different behaviours.

A range of different models and theories have been applied in health psychology and were therefore necessarily considered in terms of their relevance to the present programme of research. A review of psychological interventions that were developed on the basis of theory was conducted by Michie et al.(2008) and gave a framework for considering and identifying which might underpin the research or offer further insight to findings.

2.1 Theories of Behaviour

Based on the prior Theory of Reasoned Action (Fishbein & Ajzen, 1975), a theoretical model of behavioural determinants was provided in the mid 1980's by the Theory of Planned Behaviour (TPB) (Ajzen, 1985). The TPB has been extensively used in trying to understand and explain human behaviour (Conner & Norman, 2005a) and therefore may give insight into how people assess QoL. The model states that attitudes towards behaviour, subjective norms in relation to the behaviour, and perceived behavioural control predict any intention to act. Intention is, in turn, considered the main predictor of subsequent behaviour. Just as the WHOQOL definition of QoL (The WHOQOL Group, 1995) asserts that people assess their QoL within the context in which they live, the TPB proposes that attitudes are dependent upon beliefs about the outcomes of behaviours; norms stem from perceptions of others' preferences; and behavioural control is influenced by beliefs about control factors both internal to the individual and originating externally, in the individual's environment. Whilst providing a clear explanatory model, whether it is sufficient in explaining behaviour has been the subject of some debate. For example, it has been pointed out that other factors such as moral norms, self-identity and the role of the intention-behaviour gap are missing in the model, but may be influential in translating actions into behaviours (Rodham, 2010).

Behavioural intentions may be important in understanding self-judgements of QoL as they are intrinsically associated with peoples' "*goals, standards and concerns*", as specified in the WHOQOL definition of QoL (The WHOQOL Group, 1995, p. 1405). The Health Action Process Approach theory (Schwarzer, 1992, 1999; Schwarzer & Fuchs, 1995; Schwarzer & Renner, 2000) has attempted to explain the intention-behaviour gap in terms of the operation of two phases – a motivation (or pre-intention) phase and a volition (action) phase. The intention-behaviour gap is also addressed in the theory of Implementation Intentions. This strategy uses if-then plans to connect opportunities to act with behavioural intentions and has been postulated to support goal achievement (Gollwitzer, 1993). Whereas a goal intention specifies what action is intended, implementation intentions specify the "when", "where" and "how" of the action. Empirical studies have found that forming implementation intentions is effective

in the achievement of goal outcomes (Armitage, 2004; Chapman, Armitage, & Norman, 2009; Gollwitzer & Sheeran, 2006; Sheeran, 2002).

As seen in the WHO (1995) definition of QoL, goals are elemental in shaping individual's self-judgements of QoL, and therefore factors that influence goal setting and goal achievement were considered relevant to the present research. Allied to implementation intentions, the concept of perceived self-efficacy has also been suggested to be considered important for action towards goals. Perceived self-efficacy is concerned with people's beliefs in their capacity to accomplish particular actions (Bandura, 1977) and these self-related cognitions have been found to be critical in terms of processes of motivation and planning (Lippke, Wiedemann, Ziegelmann, Reuter, & Schwarzer, 2009; Luszczynska, Tryburcy, & Schwarzer, 2007; Reuter et al., 2010; Scholz, Nagy, Göhner, Luszczynska, & Kliegel, 2009). Self-efficacy has been shown to mediate between intentions and actions and has been asserted to determine the effort spent in initiating and maintaining a behaviour (Joekes, van Elderen, & Schreurs, 2007; Marks, Allegrante, & Lorig, 2005; Sniehotta, Scholz, & Schwarzer, 2005). It has also been suggested that people with high self efficacy are more likely to achieve their targets because they tend to set clear goals, monitor their behaviours optimistically and put considerable effort into goal attainment (Sniehotta et al., 2005).

2.2 Theories of Self-Regulation

Self-regulation has been defined in psychology as those “...*mental and behavioural processes by which people enact their self-conceptions, revise their behaviour, or alter the environment so as to bring about outcomes in it in line with their self-perceptions and personal goals*” (Fiske & Taylor, 1991). This process has also been postulated to have the aim of ensuring wellbeing and to offer a model for explaining QoL (Boersma & Maes, 2006).

Self-regulatory theories assert that behaviour is goal directed and controlled by systematic processes of comparing performance with goals and implementing strategies to reduce any sensed discrepancy between the two (Michie, Hardeman, et al., 2008).

Carver and Scheier (Carver & Scheier, 1982, 1998) proposed a theory of self-regulation which centres around the concept of the feedback loop, whereby current and desired states are compared, with consequent behavioural outputs leading to changes in individuals' perceptions.

Reducing sensed discrepancies and feedback loops have been frequent themes in social psychology historically. For instance Social Comparison Theory (Festinger, 1954; Suls & Wills, 1991) suggests that individuals make sense of their world by comparing themselves with others (S. E. Taylor, Lichtman, & Wood, 1984). People attempt to regulate their emotions by comparing themselves with others they consider to be worse off (downward social comparisons) in order to make them feel better about their own circumstances. Similarly comparing with those considered better off (upward social comparisons) can help to meeting emotional needs by providing motivation, hope and inspiration and thus support problem-solving efforts (S. E. Taylor & Lobel, 1989). The concept of social comparisons illustrates one of the ways by which individuals identify and assess external reference values. Similarly, purposive intra-personal comparisons have been proposed as a way in which self-evaluation becomes salient in self-regulatory strategies (Carver & Scheier, 1998).

Mental contrasting is another self-regulation strategy that is asserted to translate thoughts about expectations of success and the value of incentives into a goal commitment (Stadler, Oettingen, & Gollwitzer, 2010). By imagining a desired future and reflecting on a respective negative reality this is proposed to be a means of motivating people to actively self-regulate. Mental contrasting involves 1) identifying whether a behaviour change is perceived to be achievable; 2) imagining the most positive outcome of if that change were effected; and 3) identifying and imagining the main barrier to achieving the change. When expectations of success are high, elaborating future and reality in this way is postulated to link the two and to make them accessible and this process has been asserted to create strong goal commitment (Oettingen, 2000). It has been found to be successful in facilitating behaviour change in laboratory experiments (Oettingen & Stephens, 2009).

QoL perceptions vary both between individuals and within an individual over time (Carr et al., 2001). Periods of adversity, such as ill health, create a threat to the continuation of an individual's preferred and desired activities. Yet those faced with such threats often fail to show evidence of the consequent reduction in their QoL (Carver & Scheier, 2000). One explanation for this phenomenon is provided by the concept of response shift (Sprangers & Schwartz, 1999). This model describes how individuals facing changed life circumstances may recalibrate their internal standards, values or their concepts of QoL so as to evaluate their situation according to different criteria from those held before. In considering response shift in relation to self-regulation, Carver and Scheier (2000) postulated that when encountering ill health, people initially experience distress and renew their efforts to right things. The suggestion is that if this is found to be unfruitful, they may, over time, seek to scale back the point of reference again which they compare their current condition. By so doing, they refocus their behavioural aspirations and even the choice of goals which they wish to pursue. The result is a shifted reference point for affect. Carver and Scheier (2000) assert this principle of resetting of reference values accounts for the same recalibration concept proposed by Sprangers and Schwartz (1999). Recalibration is therefore a mechanism which enables coping with those traumas that may cause permanent changes in lives.

The Self-Regulation Theory (SRT) of Carver and Sheier (1982, 1998) was chosen as the theoretical framework for the present programme, and will be presented in section 2.3 below. As discussed in Chapter 1, the WHOQOL instruments enable the measurement of scores relating to individual self-judgements of both core QoL and the importance of its various aspects. In turn, both core QoL and Importance scores can be compared. In the same way, Carver and Scheier's SRT theory is centred on a feedback process in which an individual compares their current and desired states, each reflecting similar concepts to core QoL and Importance. There exists, therefore, a compatibility between the two approaches and this was key in choosing SRT to apply to the present programme of research. Furthermore the WHO definition of QoL (The WHOQOL Group, 1995) highlights the importance of goals, standards, expectations and concerns in peoples self-judgements of QoL and each of these concepts is also acknowledged in SRT, as will be elucidated in section 2.3.3 below.

2.3 Carver and Scheier's Control Theory (1982) & Self-Regulation Theory (1998)

Control theory was presented in the 1980's as a model of self-regulation that could be useful in the conceptualization and analysis of human behaviour (Carver & Scheier, 1982). The origins of the theory are found in the work of Wiener (1948) who utilized the term cybernetics to describe control and communication in animals and machines. A distinguishing feature of his model was the use of feedback information to adapt or steer the entity toward a goal. He suggested that when feedback is utilised in this way, leading to changes within a behavioural or operational system, it appears to be self-organizing.

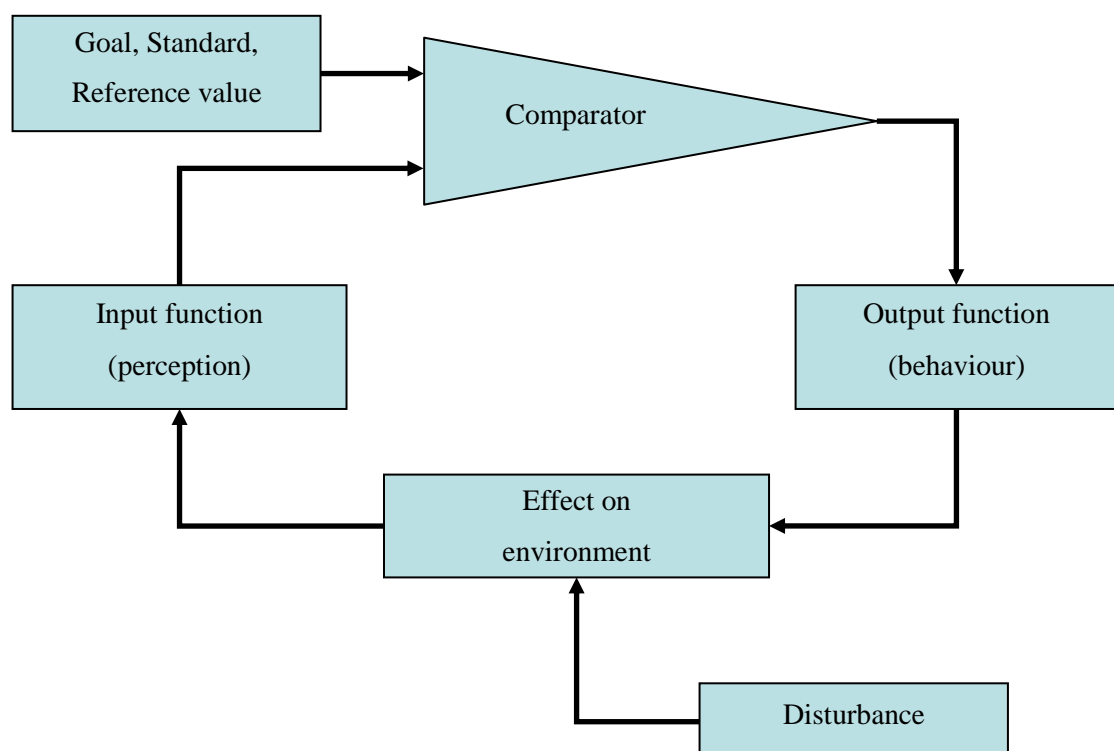
Carver and Scheier's (1982) control theory model arose from previous research concerning: how individual's actions are determined; the cognitive bases of therapeutic behaviour change; and analyses of individuals' attempts to maintain physical well being. It can be thought of as a homeostatic construct as it argues that the basic function of self-regulation is to reduce sensed discrepancies between an individual's judgement of their actual and desired states, as mentioned above. More latterly, control theory has been expounded upon in terms of the influence of optimism and affect, and is now more commonly referred to as Carver & Scheier's (1998) Theory of Self-Regulation (SRT).

2.3.1 The feedback loop

The basic unit of SRT is the negative feedback loop, as illustrated in Figure 2.1. Within the loop the input function represents the perception or sensing of a present condition whilst the reference value provides information about what is desired or intended (i.e. a goal). The comparator component is the point of reference where the input and reference value are compared, with the output function specifying the subsequent behaviour initiated. Change created which leads to a different input perception is represented by the effect on environment component, and disturbance factors are those external influences that may impinge upon the loop.

This operation of the loop can be elucidated with a hypothetical example. For instance, a person with rheumatoid arthritis, might find their condition has led to their gradual withdrawal from social activities. Their recognition of the limited nature of their leisure pursuits could be said to represent the input value of the feedback loop. Identifying a more extensive social life that they would prefer to have would therefore represent the reference value. The comparator component of the loop would be the point at which they compare their current perception of the extent of their leisure activities with the “ideal” provided by the reference value. As a result of this comparison they may decide to adjust their behaviour in order to reduce the discrepancy between their current and ideal social life, perhaps by joining a book club or other social group. This would represent fulfilment of the output function of the feedback loop. Regular attendance at the book group would create a change in the general level of their social activity (the effect on environment element of the loop) which in turn would lead to a new perception of their level of social engagement.

Figure 2.1 The feedback loop (Carver and Scheier, 1982, 1998)



The feedback loop is termed negative because of its purpose to negate or reduce sensed deviations between a current state and a comparison value. Conversely a positive feedback loop is suggested to operate in the same way as the negative feedback loop but serves instead to enlarge the discrepancy perceived between the input (current) and the reference values. In this latter case, the reference value becomes one which is to avoid rather than approach. However, the avoidance of one goal or state often results in approaching something else, in which case the negative feedback loop again applies (Rasmussen, Wrosch, Scheier, & Carver, 2006).

Having stated that SRT can be thought of as a homeostatic construct, it would, however, be fallacious to assume that feedback loops do nothing more than create and maintain steady states. Whilst some reference values indeed represent static end states, others can shift and develop and thus the concept of feedback processes can be equally applied to more dynamic goals (Carver, 2004).

2.3.2 *Self-regulation theory and quality of life*

An essential premise of SRT is that individuals routinely assess their position in life by making comparison with external references. As was discussed earlier, the WHO similarly defines QoL as a broad ranging concept illustrating “*individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns*” (The WHOQOL Group, 1995, p. 1405). It was also pointed out that many other definitions of QoL have drawn comparable conclusions - for example, that QoL represents the gap between expectations and experience (Calman, 1984; Carr et al., 2001) or that it corresponds to individuals' appraisal of their current conditions compared with what they perceive to be possible or ideal (Velikova et al., 2008). Like self-regulation, QoL has also been asserted to be a dynamic concept, accommodating or adapting to changing circumstances with the aim of achieving homeostasis (Brown et al., 2004). Given these similarities, SRT has applicability for research into QoL. In section 2.3.3 below the individual components of SRT will be examined in further detail, but within the framework of the WHO definition of QoL, further illustrating the compatibility of the two approaches.

2.3.3 *Self-regulation theory and the WHO definition of quality of life*

As discussed earlier in Chapter 1, section 1.1, and in section 2.3.2 above, the WHO definition of QoL and SRT are congruent concepts. As will be seen below, the SRT model accommodates each of the fundamental elements of the WHO definition (goals, expectations, standards and concerns).

SRT and goals

The construct of personal goals is elemental in SRT just as it is specified as an important contextual factor in the WHO definition of QoL. In SRT, goals can vary in terms of level of abstraction: goals at the lowest level may be specific and concrete individual actions, whereas at higher levels they may represent more abstract statements of desired outcomes or states of being. In SRT this hierarchical organisation of goals is suggested to influence behaviour since higher-order systems provide goals to the systems just below them. In turn, higher order abstract goals are attained by achieving the more specific acts that help to define them (Carver, 2004).

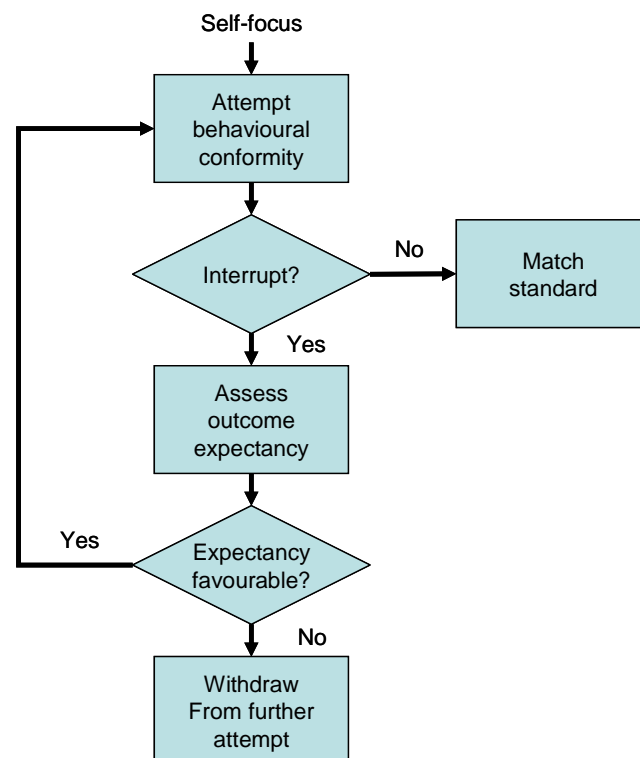
Goals may also vary in terms of importance. SRT purports that higher level goals tend to be more important and are more tied to the sense of self. It is also argued, however, that lower order goals may also have elevated value if they are central to the achievement of a more abstract goal (Rasmussen et al., 2006).

However, the identification of goals does not imply that they are then persistently pursued. SRT acknowledges that, in certain circumstances, specific goals may be simply unrealistic due to constraints that may be biologically or socially determined. For example, illness or normal ageing may have implications for physical goals. Similarly, age norms may guide life transitions and make achievement of goals more difficult where they are perceived to be incongruent with life course. Sociocultural conditions may likewise impinge upon goals, such as where financial constraints preclude the pursuit of particular aims. SRT provides for consideration of the implications of confronting unattainable goals and the associated emotional ramifications, as well as the modification or disengagement of personal goals as an adaptive strategy (Carver & Scheier, 2000, 2002).

The notion of goals is fundamental in SRT as these represent the reference value against which current states are compared. Given the centrality of this concept, measuring movement towards goals is considered a key indicator of self-regulatory effort to reduce sensed discrepancies between an individual's judgement of their actual and desired states.

SRT and expectations

Figure 2.2 The expectancy assessment process (Carver and Scheier, 1982)



Social cognition theories suggest we impose a schematic organisation on our knowledge about environments and other people. In the same way SRT suggests that attempts at discrepancy reduction are fundamentally influenced by the schemas individuals hold regarding expectations (termed expectancies). For example, when based on an individual schema, if a person's expectations are such that they believe their attempts will end in failure, they may be tempted to disengage from their efforts (and possibly to abandon the particular goal). At a more holistic level, generalized expectancies, in the form of

dispositional optimism and pessimism are a further source of influence upon whether particular goals may be approached or avoided. As such SRT assumes an expectancy assessment process, as illustrated in Figure 2.2. That expectancies influence self-judgements of QoL is also explicit within the WHO definition, as was discussed earlier.

SRT and standards

Individuals hold and refer to a multiplicity of standards in the course of their everyday lives. Examples include instructions, social comparisons, attitudes, or societal or group norms. These standards may be demanding, or less so, but all may serve as a point of reference around which an individual seeks to regulate their behaviour. In SRT, these standards inform the reference values which can, in turn, be thought of as goal constructs (Carver & Scheier, 1998, 2002). The SRT model also acknowledges that, as peoples' experiences develop, they may adjust what they expect of themselves and re-centre the system upwards or downwards in terms of reference value (Carver & Scheier, 1998). Similarly it has been asserted that, not only do standards vary across the particular behaviours to which they apply, but they also may vary in response to personal experience and serve as one of the factors against which people judge their QoL (The WHOQOL Group, 1998a).

SRT and concerns

The WHO definition of QoL includes individuals' concerns as another of the factors that influence their QoL. In a similar way, SRT acknowledges environmental factors that may impinge on the operation of an individual's feedback loop. The theory includes consideration of external "disturbance" factors that may be societally or culturally driven and which may inhibit or support self-regulatory efforts.

2.3.4 Self-regulation theory and affect

Emotional experience is another central element in SRT. Along with behaviour-guiding cognitions, SRT recognises that feelings arise from a second, simultaneous and parallel feedback process which is, in effect, checking how successfully the first process (the behaviour loop) is reducing its discrepancy. The consequent feelings generated may be positive or negative. If progress towards discrepancy reduction is below that which is

desired, negative valence arises. If progress exceeds expectation, positive valence results (Carver, 2004). The affective consequences of the feedback loop in the SRT thus suggest that measuring mood may be important in understanding its effects.

2.4 Basing Practical Interventions in Self Regulatory Theory

With increasing recognition that behavioural change interventions need to draw upon established theoretical bases, more research strategies for developing and evaluating interventions now commence with a “theory” phase before progressing to modelling (Michie, Johnston, et al., 2008). Indeed Abraham and Michie (2008) developed a theory-linked taxonomy of behaviour change techniques used in interventions. In this they identified SRT as the theoretical framework underlying a number of techniques including the prompting of specific goal setting; review of behavioural goals and feedback on performance.

Recent examples also demonstrate where SRT has been applied in interventions. For example, Thoolen, de Rider, Bensing, Gorter and Rutten (2008, p. 54) incorporated elements of SRT into a self-management course for diabetes patients, pointing out that *“self-regulation is the process through which people control and direct their actions in order to meet their goals”* and that *“self-management requires a continual trade-off between maintaining long-term health and continuing to pursue other personal goals, habits and activities that often interfere with optimal self-management”*. They found subsequent improvements for participants in terms of proactive coping, goal achievement and self-efficacy. SRT has also provided the basis of theory-driven self-management interventions for people with chronic diseases requiring self-care behaviours. Schreurs, Colland, Kuijer, De Ridder and van Elderen (2003) found positive effects on goal formation and planning for patients with asthma, diabetes and heart failure, and positive results were found for QoL in a similar study of asthma patients (Kuijer, De Ridder, & Colland, 2007). In a study of an intervention protocol designed to increase the physical activity of people with diabetes, 42% of the intervention techniques delivered were found to be associated with SRT (Michie, Hardeman, et al., 2008),

suggesting its broad application in this area. This empirical evidence, showing the efficacy of these various interventions, suggests SRT theory has been successfully applied to positive effect in healthcare.

2.5 Thesis Rationale

As discussed in Chapter 1, the current focus on PROMs and the more general concern with wellbeing in the UK, suggests that research into QoL is relevant and important. However, whilst the research in this area has been considerable over the years, studies have mainly sought to apply QoL measures to the benefit of groups, populations or services and to focus on the effectiveness and utility of this information from the viewpoint of the physician or nursing staff (Detmar, Aaronson, Wever, Muller, & Schornagel, 2000; Detmar et al., 2002; Gough & Dalgleish, 1991; Greenhalgh et al., 2005; Gutteling et al., 2008; Hilarius et al., 2008; Meadows, Rogers, & Greene, 1998; Velikova et al., 2004). It is apparent that little attention has been paid to the use of QoL information on an individual basis and in a way that facilitates peoples' understanding of their own QoL. The current emphasis on PROMs has highlighted the role that individualised outcomes can have in changing how health problems are perceived and managed both by patients and clinicians alike (Marshall et al., 2006).

The underlying premise of the present programme of research is that subjective ratings of QoL could be used in individualised ways that might have positive consequences in terms of mood, QoL-related goal orientation and wellbeing. This proposition arose from the findings of a previous study by Llewellyn and Skevington (2010), which took a person-centred approach to QoL. Using the WHOQOL-BREF questionnaire (Skevington, Lotfy, & O'Connell, 2004; The WHOQOL Group, 1998a) they examined the perceptions of QoL held by those with arthritis and their "significant others" who offered them support. In this study participants were asked a number of questions about the impact of arthritis on their QoL and were offered, for their interest, a graphical output of their QoL self-ratings. In a supplementary post-study evaluation some participants suggested that they had found taking part in the study to be beneficial.

Identifying ways in which taking part in the study had changed the way they thought about their QoL, these participants described how completing the QoL questionnaire and discussing QoL had assisted them to focus on the positive aspects of their lives and gave them a sense of control over the consequences of arthritis. From these small scale findings the proposition was developed that giving feedback on subjective ratings of QoL has potential to have a positive effect on wellbeing.

2.6 Research Aims

The aims of this programme of research were to develop the basis of a self-management tool, by feeding back QoL information at a person-centred level, to promote wellbeing. Its objective was to develop a protocol for giving individualised feedback on self-ratings of QoL and to test whether it has a beneficial psychological effect. It is anticipated that this protocol could be further developed and applied in a number of settings including in primary care where it may have the potential to facilitate the self-management of chronic illness. As has been previously found, the application of self-management programmes allows patients to consider new ways of coping and therefore can provide a basis from which to successfully achieve positive psychological adjustment (Lorig, Ritter, & Plant, 2005; Lorig et al., 2001; Osborne, Hawkins, & Sprangers, 2006). The individualised feedback in this programme of research was similarly intended to provide a foundation for self-management. Improving people's understanding of their QoL and those aspects which are important to them, in a way that has a positive psychological effect, may also help them to recognise those which areas might be a priority for action i.e. those aspects they believe are important but where their QoL could be better.

The research was grounded in the existing literature demonstrating the beneficial application of PROMs and QoL data, and on the prior findings of Llewellyn and Skevington (2010) that the process of thinking about one's own QoL may instigate positive psychological adaptation. Carver and Scheier's (1982, 1998) SRT model was used as a theoretical framework in which to interpret findings.

The overall hypothesis was: the strategic use of a theoretically-driven QoL self-management intervention will have a positive effect on individual's later judgements about their QoL, on their emotional state, and on their perceptions of moving towards or away from their QoL goals. (Individual hypotheses relating to the aims of each phase of the research will be discussed in the respective chapters.)

The primary research questions of the programme of research were:

1. What effect does thinking about one's own QoL have on an individual's later assessments of his/her wellbeing?
2. Does receiving individualised feedback on QoL judgements and the importance of QoL have a positive impact on later consideration of core QoL and the importance of its various aspects, mood and QoL-related goal orientation?
3. What reflections do individuals have in relation to thinking about their QoL and the process of individualised QoL feedback?

Within question 2, secondary research questions investigated whether verbal or written feedback methods demonstrated differential effects and if effects differed according to whether participants were healthy or chronically ill. An additional psychometric analysis of the QoL measures aimed to establish their reliability and validity for the purposes of ascertaining the accuracy and precision of the measures used.

2.7 Research Phases

The MRC's guidance on complex interventions was introduced at the start of this chapter (Medical Research Council, 2000, 2008). This advice document not only recommends that any intervention has a coherent theoretical basis but also suggests that its systematic development should adopt a carefully phased approach involving the identification of existing evidence and the modelling of processes and outcomes (Craig et al., 2008a). It states also that this latter stage may require a series of studies, each of which can progressively refine the intervention's design. Accepting this framework, a

phased approach was adopted in the current research for investigating the effects of individualised feedback on QoL.

Study 1: Methodological development study (Chapter 3)

Aim: To develop the methodological aspects of potential experimental and feedback conditions by evaluating novel components to determine their feasibility, face validity and acceptability to participants.

Study 2: The effects of thinking about quality of life (Chapter 4)

Aim: Informed by the results of study 1, to conduct a “proof of principle” pilot study to investigate whether the cognitive process of thinking about QoL could, in itself, have a subsequent effect on self-ratings of QoL, mood and QoL-related goal orientation. This was necessary in order to have confidence that any effects resulting from individualised feedback were due to that process, not due to the inherent thinking processes involved in completing the QoL questionnaires.

Study 3: Investigating the effects of providing feedback on subjective judgements of QoL (Chapter 5)

Aim: Following the findings of Study 2, to investigate the outcomes of two different feedback methods in terms of intervention effects on wellbeing, mood and QoL-related goal orientation, and to identify whether effects differ between healthy individuals and those who report a chronic physical illness.

Psychometric analysis of QoL measures (Chapter 6)

Aim: Using data from the three prior studies, to establish the psychometric properties of the QoL measures used throughout the programme of research.

Study 4: Investigating participants’ reflections on receiving individualised feedback (Chapter 7)

Aim: To follow up on the effects of the individualised feedback intervention by examining individuals’ reflections on the process used, and to explore the potential for its future application in the light of results.

With the exception of the psychometric study (Chapter 6), each study in the thesis employed a mixed methods design. Mixing methods is a pragmatic strategy that allows the combining of rigorous approaches which seeks to capitalise on the complementary nature of qualitative and quantitative research (Ring, Gross, & McColl, 2010). By using mixed methods in this way, it is suggested that broader perspectives can be gained from the different types of data within a study (Creswell, 2009) and that aspects might be illuminated in ways that otherwise might remain overlooked (Protheroe, Bower, & Chew-Graham, 2007). It has also become a more common approach in health research (Adamson, 2005), reflecting the complexity of factors influencing individual health.

In Chapter 1, definitions of QoL were examined and the measurement of the construct considered. Applicable theories and the aims and rationale for the research were discussed in the present chapter. Adopting the WHOQOL definition of QoL and the theoretical framework of SRT, the next five chapters present individual studies within the programme of research. All findings are drawn together and discussed in the final chapter of the thesis together with the overall conclusions and implications stemming from the research.

CHAPTER 3. STUDY 1: METHODOLOGICAL DEVELOPMENT OF INTERVENTION COMPONENTS

3.1 Introduction

To begin to develop an intervention in healthcare, researchers must have a clear understanding of the nature of its components and those factors that may affect its outcomes. Lack of due consideration at the design stage, whilst asserting that a particular intervention is reasonably straightforward, may deleteriously affect the integrity of the research and confidence in its results. Furthermore, it is considered that there is no definitive boundary between what might be termed simple and complex interventions (Craig et al., 2008a, 2008b) and that the same rigour should be applied, regardless of the level of complexity. Complex interventions are considered in the literature to be those that are made up of several interacting components, be they behavioural, technological or organisational and which may be present in both the experimental and control conditions. Moreover, the range and nature of behaviours required of those receiving or delivering the intervention may add further complication, so too the number and variety of outcomes. All these factors may act both independently and interdependently leading to difficulty in the evaluation of the overall intervention due to an inability to identify the key relationships between components and the points at which the “active” ingredients are effective. As such, understanding interventions involves the analysis of those moderators (conditions) and mediators (processes) that affect intervention outcomes.

In health care, complexity is introduced where individuals’ behaviours and actions are not completely predictable – where individual preferences and decision making abilities introduce uniquely interconnected systems of rules and patterns of behaviours. This applies not just to the behaviour of patients but also to the care provided by health professionals to those individuals – each with different physical, social and

psychological needs (Rowlands, Sims, & Kerry, 2005). Despite the challenges in the evaluation of complex interventions, they are widely used in the health service, in public health practice and in social policy interventions that have implications for health (Craig et al., 2008a). Examples of such applications are given in Figure 3.1.

Figure 3.1 Examples of the application of complex interventions (M. Campbell et al., 2000)

- Service delivery and organisation:
 - Stroke units
 - Hospital at home
- Interventions directed at health professionals' behaviour:
 - Strategies for implementing guidelines
 - Computerised decision support
- Community interventions:
 - Community based heart disease prevention
 - Community development approaches to improve health
- Group interventions:
 - Group psychotherapies or behavioural change programmes
 - School based interventions
- Individual patient interventions:
 - Cognitive behavioural therapy (e.g. for depression)
 - Health promotion (e.g. alcohol reduction / dietary change)

Craig et al. (2008a) suggest that, having adopted a theory and using the optimum available evidence, best practice is then to systematically test a proposed intervention using a carefully phased approach. In addition to mapping out the tasks and processes on paper, the planning phase can provide an opportunity to uncover aspects of the research that require refinement. While expert analysis of a proposed study can be useful in highlighting potential improvements, conducting a practical pre-test may be the best way to identify problems with a methodology's design (Addington-Hall, 2007). This

guidance informed the present study in conducting a pre-test to confirm the acceptability and feasibility of the potential intervention design.

Conventional pre-tests often take the form of a “dress-rehearsal” of the study proper and are based on the assumption that problems will be signalled by some obvious consequence, for example, anomalies in the answers to questions or responses to tasks. However best practice involves the more comprehensive systematic development of a study and a range of evaluations that seek to expose problems such as acceptability, compliance, and delivery (Craig et al., 2008a). As Bryman (2008, p. 247) concludes , whilst “*it is always desirable to conduct a pilot study*” this is “*not solely to do with trying to ensure that survey questions operate well; piloting also has a role in ensuring that the research instrument as a whole functions well.*” Thus, not only can piloting help to identify and fix problems experienced by participants, it will also have value in revealing potential difficulties for the researchers who will be administering the study or intervention. It is hoped that by using a well planned pre-test or pilot version of a protocol, the reliability of an experiment can thus be improved (Neuman, 2006). Indeed Rowlands, Sims and Kerry (2005) consider modelling a proposed intervention, and evaluating each of the constituent parts, to be an essential step in trial design, and this was the intention of the present study.

A number of approaches can be used for pilot testing and have been summarised by Presser et al. (2004). For example conventional testing involves de-briefing with researchers following the administration of the methodology. However, this can rely on the experience and sensitivity of researchers and their ability to identify problems. It may also be the case that certain problems or misunderstandings are simply not evident to researchers observing respondents’ behaviour. So researcher debriefing alone may not be sufficient for a comprehensive testing approach. Another testing method is cognitive interviews, using “think aloud” techniques to determine respondents’ thoughts. This approach may be very helpful in uncovering the thought processes involved in a task and can reduce the potential for researcher bias, however it is an artificial and labour-intensive task for which respondents may require prior training. A range of other testing methods include behaviour coding, where task behaviours are reviewed or monitored;

response latency (i.e. the time taken to complete a task); and vignette analysis, where respondents reflect on a hypothetical situation. However, it has been recently argued that healthcare research should incorporate more collaborative patient involvement in the methodological activities of the research process (Staniszewska, Haywood, Brett, & Tutton, 2012). Participatory testing, where respondents are directly asked about their interpretations and experience of the study tasks, is one such approach. This, together with researcher reflections, may provide a more thorough assessment of study design and which elements and processes would benefit from further consideration. In addition, evidence from pilot testing that a proposal has been deemed to be acceptable to potential participants can alleviate anxieties about potential harm. This is particularly the case where research ethics committee members are asked to consider studies that are intrusive or require the recruitment of “vulnerable” people and is asserted to be especially important for psychological studies (Speck, 2007).

Given the recommendations in the literature, it was apparent that the methodological development of a novel QoL feedback intervention should therefore include testing of its potential components. Systematically evaluating these aspects to establish their feasibility and acceptability to participants, was therefore considered necessary to inform and add rigour to later studies examining the effects of the intervention.

3.1.1 Study rationale

Study 1 sought to develop the methodological aspects of the proposed feedback intervention by evaluating any novel components to determine their feasibility, face validity and acceptability to participants. The prior development of the WHOQOL questionnaires had involved focus groups and “lay” question-writing panels and their good psychometric properties have already been established in a number of studies (these will be described in more detail in section 3.2.1.2 of the current chapter). It was therefore not felt necessary to evaluate the design of the WHOQOL questionnaires themselves, but to concentrate on the proposed new feedback mechanisms and other novel methodologies that had not been previously tested.

A participatory approach, in the form of respondent debriefing, was considered the most pragmatic technique for this study. To assist participants in evaluating the study tasks, post-task evaluation questionnaires and general discussions with the researcher served to guide their deliberations. Additional data were obtained from the reflexive insights of the researcher. Statistical analysis of outcome data from any of the measures within component tasks (for example WHOQOL-BREF self-ratings) was determined to be outside the remit of this investigation, but was used later in the programme of research alongside data from other studies (see Chapter 6).

For Study 1, older adults (aged 50+) were chosen as the sample population. Ageing presents a number of potential challenges, for example, bereavement, poor quality of death, reduced mobility and health, depleting social networks and reduced income (Brown et al., 2004). Moreover, successful ageing has been defined as “*the ability to take care of oneself and to find one’s own way, as one grows old*” (Steverink, Lindenberg, & Slaets, 2005, p. 235) and has been postulated to equate with the idea of a good QoL (Bond & Corner, 2004). Allied to this, the World Health Organisation (2002, p. 12) has defined active ageing as “*the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age*”. A population of older adults was therefore determined to be representative of people who may have to adjust their goals and reconceptualise their views on their QoL in order to maintain positive psychological wellbeing. Furthermore, as individuals, older adults may stand to benefit from measures to enhance their adjustment abilities and this population was thus considered an appropriate group with whom to begin to develop a self-management tool for the promotion of wellbeing.

3.2 Method

3.2.1 Study design

The study followed a mixed methods design, employing both quantitative and qualitative techniques. The outcome measures made considerable use of labelled ordinal response scales which asked respondents to assess the tasks undertaken. Likert scales

generally have five- to seven-point ordered response categories and are utilized because they are easily understood (Bowling, 2005c). Likert-type scales were also employed in an attempt to ease respondent burden, given that this study contained multiple components and involved a considerable number of tasks. However, open-ended questions were also incorporated to elicit qualitative data. It was intended that this would provide an opportunity to also explore the breadth and depth of individual reflections and perceptions. The aim of using complimentary approaches in this way was to enhance the overall findings and provide a more comprehensive view of the acceptability and feasibility of the tasks under examination.


Participants were asked to undertake a number of tasks which they were subsequently asked to evaluate. These tasks are elucidated below:

3.2.1.1 Task 1: Free-form writing task about quality of life


This task was designed to promote individuals' unstructured consideration of QoL. The psychological process asked of them was therefore the cognitive process of thinking about one's own QoL. Although it was not proposed as a future component in a QoL feedback intervention, it was included in order to establish its potential to act as a control condition in later studies in the research programme.

To assist in understanding the meaning of the concept of QoL, participants were firstly asked to read a short piece of written information about it, based on the World Health Organisation's definition. Examples were given of those aspects of life that are often considered to make up an individual's sense of wellbeing and a description of the influence of their expectations. Participants were then asked "*In your own words please could you describe your quality of life?*" The pro-forma used in this task is given in Figure 3.2.

Figure 3.2 Task 1: Free-form writing task about QoL



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Quality of Life

Quality of life is about how people view their life in terms of their goals, expectations, standards and concerns. It is often considered to relate only to physical or mental health but can really include all those aspects of life that make up our whole sense of well-being. This includes things like friendships, support, where we live and work. So how we assess our quality of life very much depends on the circumstances or situations in which we find ourselves as well whether we feel healthy and able.


It is also generally suggested that that quality of life is related to the expectations we have for ourselves – about whether we have achieved what we had thought we might and about whether we see ourselves in a way we might have hope for. These expectations are to some extent based on the experiences and events we have faced in life. These experiences put our views of ourselves into a sort of context and help us make judgements about what matters to us and whether we then consider our well-being to be good or poor.

There are many ways of measuring quality of life, but they all depend on people making their own judgements. No-one can tell you how you think about your quality of life. Other people can make estimates for you, but you are the only one who really knows how you feel about your life.

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When researchers look at quality of life they are often interested in two things, firstly how people rate the various aspects that make up their quality of life and secondly, how important each aspect is to them. For example, someone may find it difficult to sleep properly so they would rate their quality of life for this as poor. However, for them this might not be a problem so they would say that it doesn't matter to them, that it is not important. In another case someone might rate their health as very good but they are very concerned to keep it that way and so it is really important for them. Just because it is already good doesn't mean it isn't very important to how they view themselves.

In your own words, please could you describe your quality of life below:

Thank you for your help.

2

3.2.1.2 Task 2: WHOQOL-BREF and WHOQOL Importance questionnaires with feedback


This task was designed to promote individuals' consideration of their own QoL in a systematic way, using the structural framework of a questionnaire – the WHOQOL-BREF (The WHOQOL Group, 1998a), see Figure 3.3. The WHOQOL-BREF questionnaire is an extracted short form of the full WHOQOL-100 questionnaire (Skevington, Lotfy, et al., 2004). It contains 26 items, one from each facet of the WHOQOL-100 plus two general items. The facets of the WHOQOL-BREF are subsumed within a four-domain structure: physical health, psychological, social relationships and environment, as shown in Figure 3.4. As with the WHOQOL-100, five point Likert-type interval scales are attached to each item. Both the WHOQOL-100 and the WHOQOL-BREF have been established to be reliable and valid both internationally and in the UK and are considered to have wide ranging uses in clinical trial and clinical settings as well having applications in a variety of service settings (Skevington, Lotfy, et al., 2004). The WHOQOL-BREF has been used to assess the QoL of people with a range of conditions and diseases, for example HIV (Chandra, Deepthivarma, Jairam, & Thomas, 2003), liver transplantation (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000), rheumatoid arthritis (W. Taylor, Myers, Simpson, McPherson, & Weatherall, 2004), breast problems (Van Esch, Den Oudsten, & De Vries, 2011) and hip and knee replacement (Ackerman, Graves, Bennell, & Osborne, 2006).

A number of studies have established that the WHOQOL-BREF has good psychometric properties. Test-retest reliability has been established as good. With samples of both ill and well people, Pearson r correlations between time points have been found to be significant and positive, ranging from 0.66 for the physical health domain to .87 for the environment domain (Skevington & McCrate, 2012; The WHOQOL Group, 1998a). With a sample of patients with breast cancer, Van Esch et al. (Van Esch et al., 2011) also found Pearson r correlations ranging from .75 for the physical health domain to .82 for the social domain. Internal consistency, as measured with Cronbach's alpha, has been determined to be adequate to good ($\alpha > 0.70$) and construct validity is also good ($r = 0.46 - 0.67$ between domains) (Skevington, Lotfy, et al., 2004; The WHOQOL Group, 1998a). Also, the WHOQOL-BREF has been established to be sensitive to change: for

Figure 3.3 Task 2: WHOQOL-BREF questionnaire

WHOQOL-BREF

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	Equations for computing domain scores	Raw score	Transformed score	
			4-20	0-100
Domain 1	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$	=		
Domain 2	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$	=		
Domain 3	$Q20 + Q21 + Q22$ $\square + \square + \square$	=		
Domain 4	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square$	=		

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1

ABOUT YOU

Before you begin we would like you to answer a few general questions about yourself: by **circling** the correct answer or by **filling in the space provided**.

What is your gender? **MALE** / **FEMALE**

What is your date of birth? ____/____/____. (day/month/year.)

What is the highest education you've received? **None at all**
 Primary school
 Secondary school
 Tertiary

What is your marital status? **Single** **Separated**
 Married **Divorced**
 Living as married **Widowed**

Are you currently ill? **YES** / **NO**

If something is wrong with your health what do you think it is?

Please write your illness(s) or problem here: _____

Instructions

This questionnaire asks how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks**. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderately	A great deal	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You should **circle** the number that best fits how much support you got from others **over the last two weeks**. So you would circle the number 4 if you got a great deal of support from others as follows:

	Not at all	Not much	Moderately	A great deal	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle the number 1 if you did not get any of the support that you needed from others in the last two weeks. Please read each question, assess you feelings, and **circle** the number on the scale for each question that gives the best answer for you.

Figure 3.3 Task 2: WHOQOL-BREF Questionnaire cont.

		2				
		Very poor	Poor	Neither poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very Dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the last two weeks**.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things **in the last two weeks**.

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

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		3				
		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the last two weeks**.

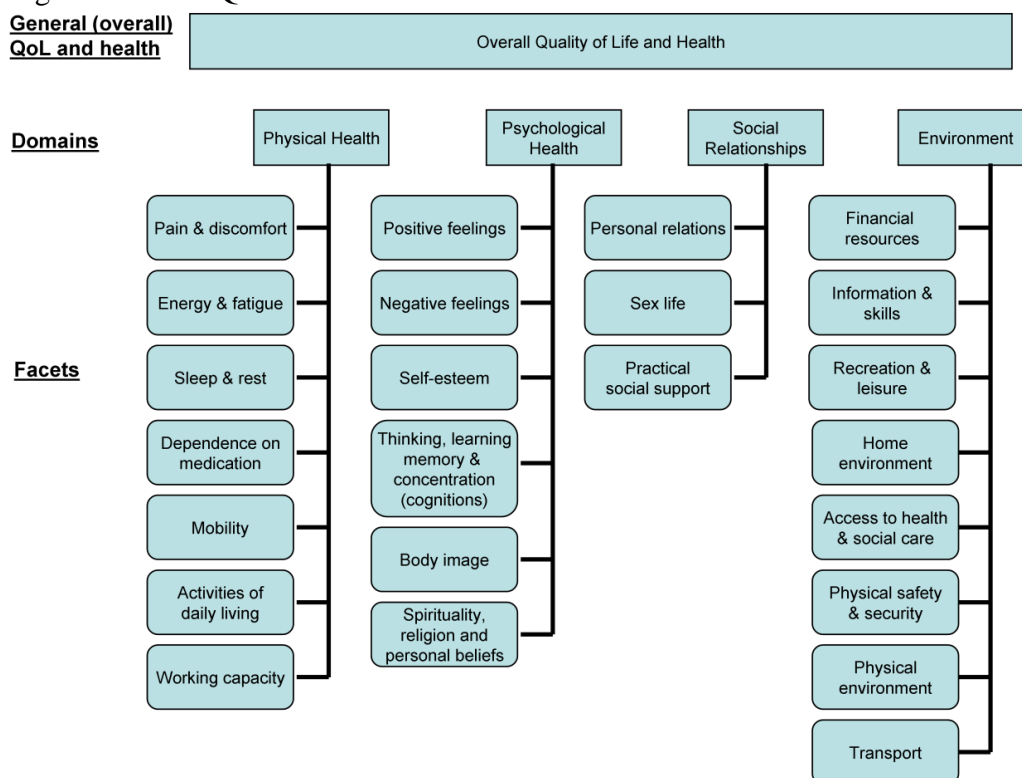
		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form? **YES / NO**

THANK-YOU FOR YOUR HELP

example, using the standardised response mean, O’Carrol, Smith, Couston, Cossar, & Hayes (2000), found large effects on all four QoL domains (0.43 – 0.92) in patients undergoing liver transplantation.

Figure 3.4 WHOQOL-BREF domains and facets



In a recent study, the WHOQOL-BREF was again determined to have between very good and excellent psychometric properties and to be suitable for use in individual assessment (Skevington & McCrate, 2012). Further it is considered to be a generic measure that permits valid comparison between different groups (W. Taylor et al., 2004).

In the present study participants were also asked to consider the importance they attached to each QoL aspect by completing the WHOQOL Importance questionnaire (abbreviated version). This also contains 26 items, one for each of the facets included in the WHOQOL-BREF and five-point Likert-type scales allow respondents to rate the importance of each item from “not important” to “extremely important” (see Figure 3.5). As stated in Chapter 1, although the importance questionnaire has recently begun to be applied to measure the importance of QoL for particular populations, the psychometric properties of measure have not yet been studied in depth.


Figure 3.5 Task 2: WHOQOL Importance questionnaire

1

ID _____

WHOQOL IMPORTANCE QUESTIONS

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UK WHOQOL IMPORTANCE QUESTIONS

The following questions ask about **how important** various aspects of your life are to you. We ask that you think about how much these affect your quality of life. For example one question asks about how important sleep is to you. If sleep is not important to you, circle the number next to "not important". If sleep is "very important" to you, but not "extremely important", you should circle the number next to "Very important". Unlike earlier questions, these questions **do not refer only to the last two weeks**.

1. How important to you is your overall quality of life? (ImpG.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

2. How important to you is your health? (ImpG.2)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

3. How important to you is it to be free of any pain? (Imp1.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

4. How important to you is having energy? (Imp2.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

5. How important to you is restful sleep? (Imp3.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

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6. How important to you is it to feel contented? (Imp4.2)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

7. How important to you is being able to think through everyday problems and make decisions? (Imp5.2)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

8. How important to you is feeling positive about yourself? (Imp6.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

9. How important to you is your body image and appearance? (Imp7.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

10. How important to you is it to be free of negative feelings (sadness, depression, anxiety, worry...)? (Imp8.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

11. How important to you is it to be able to move around? (Imp9.1)

Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

Figure 3.5 Task 2: WHOQOL Importance Questionnaire cont.

4				
12. How important to you is being able to take care of your daily living activities e.g. washing, dressing, eating? (Imp10.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
13. How important to you is it to be free from dependence on medicines (Imp11.1) or treatment?				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
14. How important to you is being able to work? (Imp12.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
15. How important to you are relationships with other people? (Imp13.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
16. How important to you is support from others? (Imp14.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
17. How important to you is your sex life? (Imp15.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

5				
18. How important to you is feeling physically safe and secure? (Imp16.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
19. How important to you is your home environment? (Imp17.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
20. How important to you are your financial resources? (Imp18.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
21. How important to you is being able to get adequate health care? (Imp19.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
22. How important to you are chances for getting new information or knowledge? (Imp20.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
23. How important to you are relaxation and leisure? (Imp21.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5

6				
24. How important to you is your environment e.g. pollution, climate, noise, attractiveness? (Imp22.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
25. How important to you is adequate transport in your everyday life? (Imp23.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
26. How important to you are your personal beliefs? (Imp24.1)				
Not important	A little important	Moderately Important	Very important	Extremely Important
1	2	3	4	5
Thank you very much for your help				

The WHOQOL-BREF and WHOQOL Importance were intended to form the basis of the QoL feedback intervention by providing the individualised data from which graphical summary profiles could be generated. Two alternative protocols were designed for giving the feedback using these profiles. To determine the feasibility and acceptability of the components prior to their use later in the research programme, each was tested in the present study. The details of the graphical summary profile and each of the feedback protocols is given below.

WHOQOL Graphical Summary Profile

For the present programme of research, an Excel spreadsheet was developed which aggregated facet scores and calculated transformed domain scores in order to produce a graphical summary profiles for each individual participant. The formulae incorporated in the spreadsheet followed the syntax provided in the WHOQOL-BREF scoring manual to ensure reversal of negatively framed items (pain, medication and negative feelings) and appropriate substitution of average scores for missing data, subject to the prescribed minimum number of items in each domain (domain scores are not calculated where 20% of items or more are missing). To allow comparison between domains composed of unequal numbers of items, scores were transformed onto a scale from 0 to 100 (The WHOQOL Group; http://www.who.int/mental_health/evidence/who_qol_user_manual_98.pdf). A second algorithm was written for this study to similarly produce WHOQOL Importance item domain scores. This algorithm was based on that of the WHOQOL-BREF items but was necessarily adjusted, as the WHOQOL Importance Questionnaire contains only positively framed items.

From the algorithms described above, the scores from the WHOQOL questionnaires were prepared ready for presentation in a visual feedback format. For this, a graphical summary profile was derived from earlier work by the WHO Field Centre for the Study of QoL at the University of Bath. This earlier work had resulted in the development of a CD-ROM based system for use in primary care, which generated basic graphical profiles from WHOQOL-BREF data for use by clinicians (Skevington & Day, unpublished). The new graphical summary profiles contained similar graphs, but the presentation was redesigned for clarity of use with individual participants and also to accommodate the inclusion of both WHOQOL-BREF *and* WHOQOL Importance scores. A series of six graphs were devised in which blue bars represented QoL self-ratings and red triangles

represented importance self-ratings. An example of the graphical summary profile is presented in Figure 3.6. The first graph illustrates the domain scores on a 0 – 100 scale, where QoL scores at the midpoint indicate QoL is satisfactory and above 50 indicate QoL is good. Similarly Importance scores of 50 indicate moderate importance, and the higher above 50, the more important the item and vice versa. The second graph and subsequent graphs illustrate the scores for each item on a scale of 0-5. (Actual scale responses on the questionnaire range from 1 –5 where 1 is very poor QoL or very low importance and 5 is very good QoL or high importance. However 0 was included in the graphs order to identify where a score for an item was missing.)

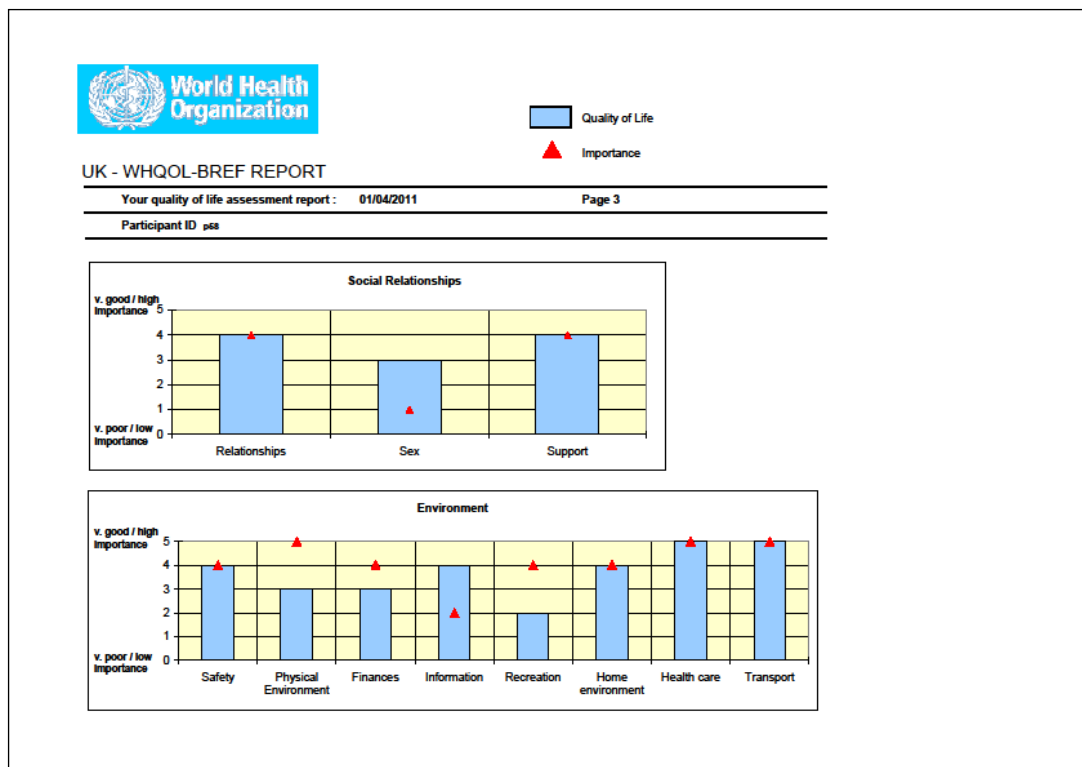
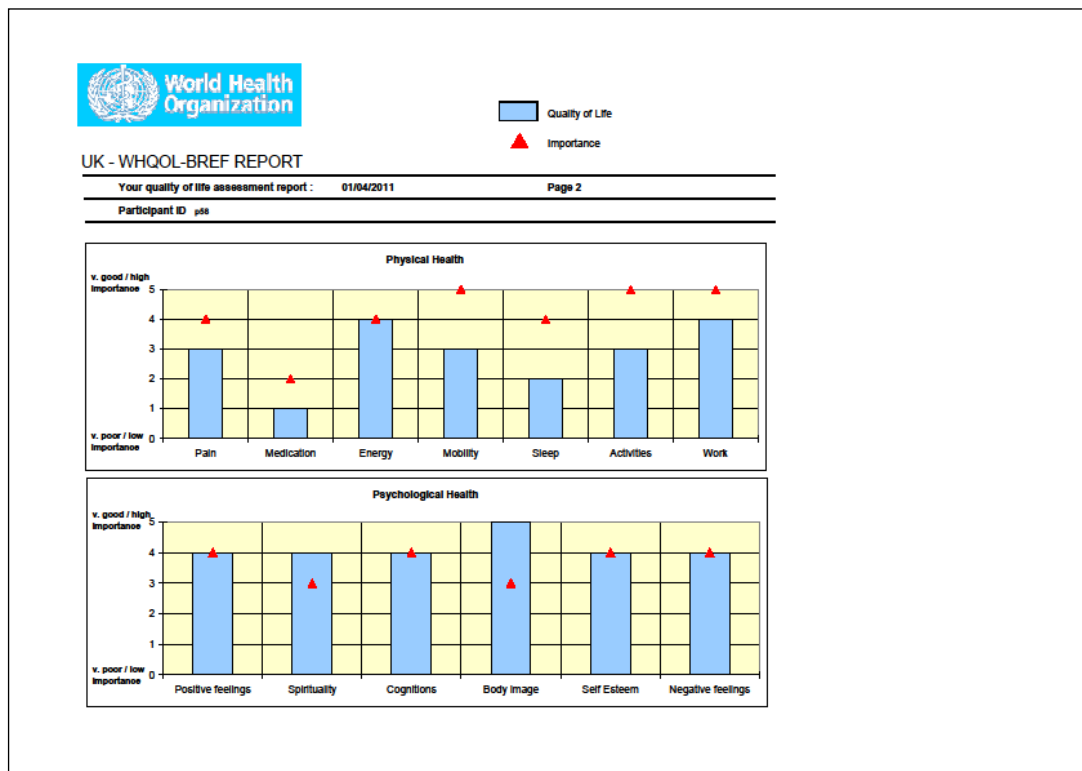
Written instructions for reading WHOQOL graphical summary profile

As one method of providing feedback, a set of written instructions was developed for this study to provide participants with guided instructions for reviewing the graphical summary profile. It was intended that this would enable them to attend to their results in a structured way. However, no further directions were given, so allowing participants to draw their own overall conclusions. The written instructions are presented in Figure 3.7.

Figure 3.6 Example graphical summary profile



Figure 3.6 Example graphical summary profiles cont.



Verbal feedback of WHOQOL graphical summary profile


As an alternative method for viewing and interpreting the graphical summary profiles, a verbal protocol was also developed. This was designed to enable an administrator to guide participants in a discussion of their QoL scores in a consistent way. The protocol allowed participants to attend to their results in much the same way as if the written instructions were followed and to facilitate their purposeful deliberation of their self-ratings. However, it also allowed the facilitator to point out different scores for different aspects and to encourage participants to comment on anything that they noted had stood out for them. To this end, a number of example additional questions were included in the researcher's script which could be used to prompt discussion of their thoughts. The full script is presented in Figure 3.8.

3.2.1.3 Task 3: Goal elicitation and assessment task.


As discussed in Chapter 1, goals are important to self-judgements of QoL. As a way of measuring goals and goal pursuit, a goal elicitation and assessment task was devised to support participants in identifying and thinking about their personal goals. This task was included to find out if it had potential as an additional component to the main QoL feedback intervention. Details of the task protocol, in the form of a script, are presented in Figure 3.9. Following a script was again intended to ensure consistency of administration. The task aimed to initially instigate participants' identification of their immediate goals. A subsequent card sorting task was designed to identify the relative importance, to the participants, of each goal and its anticipated ease of achievement. To identify those goals to be elaborated further, the task also asked participants whether they thought they would be able to address each goal in the short term (within the next two weeks), medium term (within the next three months) or long term (later than 3 months).

A goal booklet was also developed for use in this study, to encourage the more detailed specification of the short-term goal(s) (see Appendix A). Also encouraged were the formation of related implementation intentions and the assessment of self efficacy relating to the anticipated achievement of the goal(s). These concepts were discussed in Chapter 2 and were included in this task because of the evidence suggesting their importance in the achievement of goal outcomes.

Figure 3.7 Written instructions for reading the graphical summary profile



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Thank you for taking part in this project. Here is your personal feedback in the form of graphs showing how you rated each question in the WHOQOL-BREF questionnaire.

There were questions about many aspects of quality of life. The first sheet shows you an overall illustration of how all these aspects fit together. For example, questions about pain, sleep and mobility all fit into your physical health; questions about your feelings and your self esteem fit into your psychological health and so on.

To help you understand the graphs pages, here is some guidance to assist you as you read.

STEP 1

Firstly look at the graph at the top of graph page 1, called "Domain Scores". The bars show you how you rated the broad aspects of quality of life, for example, overall physical health

Important points:

- The scores on these graphs range from 0-100.
- High scores mean good quality of life. (So here, a score of 50 means you view your quality of life as acceptable. A score above 50 means that you view your quality of life as good or very good. A score below 50 means you view your quality of life as poor or very poor.)
- The four domain scores in this graph summarise the information presented in the more detailed graphs on the next pages


STEP 2

Now look at the other graph on graph page 1, called "Overall Quality of Life and Health". This shows you how you rated your quality of life and health in general. You can also see from the triangles here how important you rated these aspects to be to you.


Important points:

- For each question, possible answers range from 1 – 5.
- High scores mean good quality of life. So here, a score of 3 means you rated your quality of life as acceptable. A score of 1 or two means you rated your quality of life as poor or very poor and a score of 4 or 5 means you rated your quality of life as good or very good.
- Similarly for importance, a triangle on 3 means you rated this aspect as moderately important to you. A triangle on 1 or 2 means you rated this aspect as not important or a little important. A triangle on 3 or 4 means you rated this aspect as very or extremely important.

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STEP 3

Firstly look at the graphs on graph page 2, labelled physical health and psychological health. The bars show you how you rated these aspects of your quality of life. Again the triangles show you how important you rated these aspects to be.

Important points:

- For each of the quality of life bars a score of 3 means that you rated your quality of life as acceptable. A score of 1 or 2 means you rated your quality of life as very poor or poor, whereas a score of 4 or 5 means you rated your quality of life as good or very good.
- For the importance triangles a score of 3 means you rated this aspect as moderately important to you. A triangle on 1 or 2 means you rated this aspect as not important or a little important. A triangle on 3 or 4 means you rated this aspect as very or extremely important.

STEP 4

Finally look at the graphs on graph page 3, labelled social relationships and environment. Again the bars show you how you rated these aspects of your quality of life and the triangles show you how important you rated these aspects to be.

Important points:

- For each of the quality of life bars a score of 3 means that you rated your quality of life as acceptable. A score of 1 or 2 means you rated your quality of life as very poor or poor, whereas a score of 4 or 5 means you rated your quality of life as good or very good.
- For the importance triangles a score of 3 means you rated this aspect as moderately important to you. A triangle on 1 or 2 means you rated this aspect as not important or a little important. A triangle on 3 or 4 means you rated this aspect as very or extremely important.

If you see a zero for any aspect of any graph, this means that that particular question had not been answered.


Please note that these graphs show only the information that you gave regarding your own quality of life. They do not show anyone else's answers.

I hope that this guidance helps you to understand the graphs.


Thank you for your help.

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Figure 3.8 Verbal feedback script



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One to one verbal feedback


- **Factual description of graph of domains, each domain graph and the overall items**
 - Here is your personal feedback in the form of graphs showing how you rated each question in the WHOQOL-BREF questionnaire. You will be able to keep these.
 - There were questions about many aspects of quality of life. So here you can see how they fit together (show facet chart). For example, questions about pain, sleep and mobility all fit into your physical health; questions about your feelings and your self esteem fit into your psychological health.
 - Please note that these graphs show only the information that you gave regarding your own quality of life. They don't show anyone else's answers.
- **Domain scores**
 - Firstly I'd like us to look at the graph called "Domain Scores". The bars show you how you rated the broad aspects of quality of life, for example, overall physical health. You can also see from the triangles here how important you rated these aspects to be to you.
 - The scores on these graphs range from 0-100. High scores mean good quality of life.
 - So here, a score of 50 means you view your quality of life as acceptable. A score above 50 means that you view your quality of life as good or very good. A score below 50 means you view your quality of life as poor or very poor.
 - So for the domains:
 - This is high
 - This is low
 - The four domain scores in this graph summarise the information presented in the graphs on page 2 which we'll look at in a moment, but for now:

What do you think about this?
Is there anything that stands out for you?
Which part are you looking at?
Can you tell me what you're thinking?
What information did you draw upon to answer this question?

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- Next I'd like us to look at how you rated your quality of life and health in general. There was a question for each of these with possible answers ranging from 1 – 5 where high scores mean good quality of life or high importance.
 - So here you rated your quality of life overall as _____ and your health as _____.
 - In terms of importance, you rated your quality of life overall as _____ and your health as _____.
- **Individual domains**
 - Now I'd like to show you the graphs of your responses to each individual question. Let's look at physical health first. For each of these bars a score of 3 means that you rated your quality of life as acceptable. A score of 1 or 2 means you rated your quality of life as very poor or poor, whereas a score of 4 or 5 means you rated your quality of life as good or very good.
 - So this is very good
 - This is good
 - This is very poor
 - This is poor, and
 - This is acceptable
 - Similarly each of these stars shows how important you rated each aspect to be. So a triangle on 3 means you rated an aspect of your quality of life to be moderately important. A triangle on 1 or 2 means you rated importance to be no important, or a little important. A triangle on 4 or 5 means you rated the importance to be very or extremely important.
 - So this is extremely important
 - This is very important
 - This is not important
 - This is a little important, and
 - This is moderately important.

What do you think about this?
Is there anything that stands out for you?
Which part are you looking at?
Can you tell me what you're thinking?
What information did you draw upon to answer this question?


- Now let's look at psychological health (repeat as above), social relationships (repeat as above), and environment (repeat as above).

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Figure 3.9 Goal elicitation and assessment process



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Goal elicitation and assessment task instructions

- We're going to go on now to help you explore your personal goals in relation to your quality of life.
- Please remember there are no right or wrong answers. What I simply would like you to do is to think about your goals in terms of what has mattered to you in the last two weeks.
- Perhaps it would help to think about what matters to you at this stage in your life.
- Don't worry about how many goals you feel you have. Some people have a lot, others don't.
- I'm going to write each goal onto a card and we'll use them again in a minute.
- Do you have any questions before we begin?
- What goals do you have, relating to your quality of life, that have mattered to you in the last two weeks? **[Write goals onto individual cards]**


After goal elicitation:

- Now please lay these cards out on the table in order of importance to you with the most important at the top of the list and the least important at the bottom.
- For each card, please could you now give each goal an importance rating from 1 to 5 where 1 is very important and 5 is not at all important. Here is the scale to remind you. **[Show scale and mark rating on reverse side of each card]**
- I'd now like you to lay these cards out again, but this time in order of how easy you think they will be to achieve. Please put the easiest at the top and the most difficult at the bottom.
- Again for each one, please could you now give me a rating from 1 to 5, where 1 is very easy to achieve, and 5 is very difficult. As before, here is the scale to remind you. **[Show scale and mark rating on reverse side of each card]**


After goal sorting:

- I'm now going to write your goals into this booklet so that you can take it away with you later. While I'm doing this, perhaps you could think about any other goals you might want to add. **[Show goal booklet and write list of goals, importance and ease ratings into table on pages 1 & 2 of goal booklet]**
- So here the list of your goals. You can also see the ratings you gave each goal in terms of importance and ease of achievement.

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- Looking at this list, please could you also say which you can start in the short, medium or long term.
 - Short term means within the next two weeks
 - Medium term means within the next three months, and
 - Long term means you won't be able to start it until after the next three months.**[Write in S, M or L as appropriate on page 2]**
- Is there anything you would now like to change?
- Now I'm going to highlight the one's you have said you think you can start in the next two weeks. **[Emphasise]** We can then look at these in a bit more detail. **[Use highlighter pen to highlight short term goals]**

If a short term goal has an importance and / or ease of achievement rating above 3, suggest to participant that this is something they may wish to think about outside this exercise. Remind them we need to focus here on goals that are feasible to address and which are likely to make a difference to their quality of life.

For each individual goal:

- So one of the goals you chose was _____. **[Write verbatim into booklet]**
- What do you think you can do toward achieving this? **[Write answer verbatim into booklet]**
- When would be a good time to do that? **[Write answer verbatim into booklet]**
- **Prompt if required: When would you be free to do that?**
- Where would it be best for you to do that? **[Write answer verbatim into booklet]**
- On a scale of 1 – 10, how confident are you that you will be able to do this? **N.B. need to negotiate to 7 or above. [Circle answer on scale in booklet]**
- I'm going to write in a date here for two weeks time. On or about that date, please could you complete the rest of the questions on the page?

Repeat as required up to maximum of 4 goals.

Thank you for your help.

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3.2.2 Sample inclusion and exclusion

The study sought to recruit a small ($N=10$) heterogeneous sample of older adults, using a community sampling approach. As mentioned earlier in section 3.1, this population was chosen as representative of people who may benefit from adjustment of goals and reconceptualisation of QoL. As a feasibility study with substantial qualitative elements, it was decided that a detailed evaluation with a small number of participants, would best provide insight into the acceptability and appropriateness of the tasks. Amongst those who indicated interest in the study, quota sampling was subsequently employed with the aim of establishing a sample with an equal balance of males and females. All participants were required to be literate and able to understand the nature of the tasks. These eligibility requirements were ascertained upon meeting with participants and during the administration of the various tasks.

3.2.3 Sample recruitment

Recruitment of participants took place through the Bath branch of the University of the Third Age (U3A) - a self-managed lifelong learning co-operative for older people. "Flyers" were distributed to attendees at a lecture meeting and provision made for them to give their contact details if they were interested in finding out more. Potential participants were subsequently sent a letter giving more details about the study and informing them that they would be contacted by telephone to establish whether they wished to take part. Appointments were subsequently made with participants to meet individually either at a central Bath location or at the University of Bath.

Prior to commencing the study, approval had been obtained from the University of Bath Psychology Department Research Ethics Committee. In accordance with The British Psychological Society's Code of Ethics and Conduct (The British Psychological Society, 2009) it was made clear that participation in the study was entirely voluntary and that participants could withdraw at any time, without giving a reason and without affecting their medical or other care or legal rights. All names and contact details were securely held on paper record only. Participants were not, at any time, instructed to share their individualised feedback with any other person, although they were free to do so if desired.

Before data collection began a “sources of advice” document was compiled. This included contact details for organisations such as the Samaritans, Mind and Help the Aged / Age Concern. This was available during the data collection process in order to allow for appropriate signposting of participants to support organisations should this be deemed appropriate from comments they made or concerns they expressed.

3.2.4 Procedure

Meetings with individual participants lasted between 60 and 90 minutes. Participants were initially asked to indicate their consent to taking part by reading a participant information sheet and by completing and signing an accompanying consent form. These are given in Appendices B and C.

Participants were asked to complete the tasks in the order described in section 3.2.1 (free-form writing; WHOQOL questionnaires; written instructions for feedback; verbal feedback; and goal elicitation and assessment). On finishing each task (with the exception of the WHOQOL questionnaires which were not being assessed as a task) they were asked to complete the associated evaluation form, as will be described in section 3.2.5. After the meeting participants took away their graphical summary profiles and goal booklets. Two weeks later a letter was sent requesting completion and return of the goals booklet, together with the final evaluation questionnaires. A stamped addressed envelope was provided to each participant.

3.2.5 Measures

A series of outcome measures for this study were designed in the form of evaluation questionnaires, one for each task undertaken. These were designed to capture participants’ reflections on the various tasks and their assessments of the task’s acceptability and face validity. Likert-type scales were used to elicit subjective ratings upon each task and participants were asked to substantiate their reasoning in writing. Perspectives on how the task could be improved were invited. Details of each measure are given in the sections below and the evaluation documents are shown in Appendices D to J.

3.2.5.1 Evaluation of Task 1: Free-form writing about quality of life (Appendix D)

Participants were asked to rate their interest in the QoL information they had been given on a 0-7 scale where 1 = very uninterested and 7 = very interested. Similarly the task's helpfulness in supporting their thinking about QoL was rated from 1 = very unhelpful to 7 = very helpful. The questionnaire also captured ratings of the amount of QoL information they had been provided, from 1 = very much too short, to 5 = very much too long. Comments were also requested on how the task could be improved.

3.2.5.2 Evaluation of Task 2: written instructions for feedback (Appendix E)

This questionnaire followed a similar format as for the free-form task. However in addition to ascertaining their level of interest, the questionnaire measured how helpful they had found the written instructions. Suggestions regarding possible task improvements were requested.

3.2.5.3 Evaluation of Task 2: verbal feedback (Appendix F)

As above, participants were asked to rate their interest in the information they had been given. A measure of how helpful they felt it had been to have had someone explain the results was included and they were asked to rate the length of time the discussion had taken (from 1 = very much too short, to 5 = very much too long). Comments were again requested on how the task could be improved.

3.2.5.4 Evaluation of Task 2: graphical summary profile (Appendix G)

This questionnaire included ratings of how helpful the graphs were in supporting understanding of one's own QoL and of how helpful participants felt it would be to have the graphs to take away. Participants were also asked to specify whether they would later a) think about the graphs, b) look at the graphs again, or c) discuss the graphs with another person. In addition the questionnaire asked participants if the graphical summary profile had affected the way they thought about their QoL and included a scale to measure whether the graphs had been helpful in identifying and setting personal goals.

3.2.5.5 Evaluation of Task 3: goals elicitation and assessment (Appendix H)

In a similar format to the other measures, this questionnaire asked participants to rate the clarity of the task's instructions; the ease of goal identification; the helpfulness of the card-sorting component; the ease of identification of goal importance and the ease of attaching timescales to goals. Participants were asked to provide comments on the task, including anything they didn't understand or that could have been done differently.

3.2.5.6 Evaluation of Task 3: goals booklet (Appendix I)

This questionnaire measured participants' reflections on the ease of use of the goal booklet, how easy it was to understand, and whether it was helpful in supporting goal achievement.

3.2.5.7 Overall evaluation of study (Appendix J)

A final outcome measure was intended to capture reflections on the effects of taking part in the study. Participants were asked if taking part had changed the way they thought about their QoL and, if so, in what ways. A measure of QoL change was included (from 1 = much worse, to 7 = much better). Another scale measured how helpful participants thought taking part would be in the short term (2 weeks), medium term (3 months) and long term (more than 3 months). The questionnaire also asked participants what they had found least and most helpful and to provide any other comments.

All verbal comments made by participants during the administration of the tasks were noted. In addition, observations on the components from the perspective of the feasibility and acceptability of administration were recorded.

3.3 Analysis

The data were examined quantitatively by calculating mean scores and standard deviations for each rating scale in the evaluation questionnaires. Further statistical analysis was, however, deemed inappropriate due to the small sample size of the study.

Analysis of the evaluation of the goals elicitation and assessment task and goals booklet was not conducted due to attrition from this task (see section 3.4).

Following the methodological guidance of Donovan and Sanders (2005), qualitative data from the questionnaire evaluations of each of the components were analysed and coded in order to identify themes. As analysis sought to investigate descriptive accounts and to summarise experiences across individuals, it was determined that a thematic content analysis would be appropriate (Payne, 2007). Each written response was carefully read several times then coded for different themes using the actual words used or by reference to the general sense of the statement. The questionnaires themselves provided the initial framework for analysis since each question was intended to elicit individual's perceptions on specific aspects of each component task. With reference to the specific task being evaluated, data were coded according to emerging themes and evidencing statements were extracted.

The aim of the analysis was to investigate participants' assessments of the tasks they were asked to do and to elicit suggestions for enhancing the methodology. In addition to themes relating to task evaluation, the coding also allowed for the identification of themes relating to generic reflections on QoL as a concept. Appendix K illustrates the final taxonomy of coding and the integration of the two components – general themes relating to QoL information and themes relating to the evaluation of the tasks undertaken. In addition to the questionnaire responses, verbal comments made by participants throughout the course of the study were similarly integrated in the data and analysed for emerging themes. A tally of themes was calculated to illustrate the frequency of responses.

In the final stage of analysis, results were interpreted in terms of implications for the future methodological development of the feedback intervention. The methodological observations of the researcher were also noted and summarised.

3.4 Results

Forty-five potential participants had indicated interest in taking part in the study. Quota sampling to achieve the required 10 participants resulted in a sample of 6 females and 4 males, with ages ranging from 59 to 83 years and a mean age of 73 years. All of those who were invited subsequently took part. Further details of the demographic characteristics of the participant sample are given in Table 3.1. During the study, one participant withdrew from the free form QoL writing task and completion of the WHOQOL questionnaires and three withdrew from the goal elicitation and assessment task due to time constraints. A further three also withdrew from this latter task because they found it to be too difficult or considered it irrelevant to them, stating that they felt they did not have goals or that they could not think of any. Consequently only four participants completed the final overall evaluation questionnaire.

Table 3.1 Demographic characteristics of Study 1 participants

Participant Sample		Total	
		N=10	%
Gender	Male	4	40
	female	6	60
Highest education level completed	secondary	2	20
	tertiary	8	80
Marital Status	single	1	10
	married	4	40
	living as married	0	0
	separated	0	0
	divorced	3	30
	widowed	2	20

3.4.1 Quantitative results

3.4.1.1 Tasks 1 & 2: Free-form writing task about quality of life, WHOQOL-BREF and WHOQOL Importance questionnaires and provision of feedback.

Mean scores indicated a considerable level of interest among participants in the information they were given about QoL in the free form writing task and in the feedback

they were given regarding their own ratings of their QoL. Mean scores ranged from 5.67 ($SD=1.94$) to 5.75 ($SD=1.67$), where 1 = “very uninterested”, and 7 = “very interested”. Full results are presented in Table 3.2.

Participants found the general QoL information provided in the free form writing task only slightly helpful in thinking about their *own* QoL (Mean = 4.67 ($SD = 1.22$), where 4 = “neither helpful nor unhelpful”, and 5 = “fairly helpful”). In contrast, participants were more positive about the WHOQOL graphical summary profile on the same scale (Mean = 5.63, ($SD = 1.51$)), where 6 = “mostly helpful”).

The written instructions given to participants to assist them in reading and understanding the WHOQOL graphs were considered helpful, as was having someone explain the graphs in the verbal feedback component. Respective mean scores were 5.88 ($SD = 1.36$) and 6.11 ($SD = 0.93$), where 5 = “fairly helpful” and 6 = “mostly helpful”.

Participants indicated that having the WHOQOL graphical summary profile to take away was helpful (Mean = 5.25 ($SD = 1.67$) where 5 = “fairly helpful”). Results suggested they were less useful in helping participants to think about and set goals. Here the mean score was 4.29 ($SD = 0.49$), where 4 = “neither helpful nor unhelpful”.

Results indicated that the length of tasks, in relation to the information they were given in the free form writing task and the discussion of responses in the verbal feedback, was considered to be appropriate (writing task Mean = 3.11 ($SD = 0.33$) and verbal feedback discussion Mean = 3.00 ($SD = 0.00$), where 3 = “about right”).

3.4.1.2 Overall evaluation

The findings showed that QoL was not considered to have changed as a result of taking part (Mean = 4.25 ($SD = 0.5$)) where 4 = “about the same”. In terms of how helpful participants felt their experience would be to them in the future, the mean rating for the short term was 4.75 ($SD = 0.5$), where a score of 4 = “neither helpful nor unhelpful” and 5 = “somewhat helpful”. This was slightly higher than for the medium and long terms, where mean scores for both were 4.50 ($SD = 1.0$).

Table 3.2 Summary of ratings evaluating the free-form writing task and WHOQOL questionnaires feedback

Questions	Mean	SD	N
Evaluation of Task 1: QoL free form writing task			
How interested were you in the general information the researcher gave you about quality of life? (1 = very uninterested; 7 = very interested)	5.67	1.94	9
How did you find the information the researcher gave you about quality of life? (1 = very much too short; 5 = very much too long)	3.11	0.33	9
How helpful did you find the information in thinking about your own quality of life? (1 = very unhelpful; 7 = very helpful)	4.67	1.22	8
Evaluation of Task 2: written feedback (instructions on reading the graphs)			
How interested were you in the feedback you were given on your quality of life? (1 = very uninterested; 7 = very interested)	5.75	1.67	8
How helpful did you find it to have the instructions on how to read the graphs? (1 = very unhelpful; 7 = very helpful)	5.88	1.36	8
Evaluation of Task 2: verbal feedback			
How interested were you in the feedback you were given on your quality of life? (1 = very uninterested; 7 = very interested)	5.67	1.66	9
How helpful did you find it to have someone explain your results to you? (1 = very unhelpful; 7 = very helpful)	6.11	0.93	9
How did you find the conversation you had with the researcher about your results? (1 = very short; 5 = very long)	3.00	0.00	8
Evaluation of Task 2: graphical summary profile			
How useful were the graphs in helping you to understand your own quality of life? (1 = very unhelpful; 7 = very helpful)	5.63	1.51	8
How helpful would it be to have the graphs to take away? (1 = very unhelpful; 7 = very helpful)	5.25	1.67	8
How helpful were the graphs in helping you to think about and set your goals? (1 = very unhelpful; 7 = very helpful)	4.29	0.49	7

3.4.2 Qualitative results

The questions in the evaluation questionnaires served to guide participants' reflections on the tasks they had been asked to complete, although particular themes emerged relating to participants' QoL and their experience of thinking about it, as well as to their judgements of the procedural and structural design of the tasks. A tally of themes is shown in Table 3.3 and comments extracted to exemplify these themes are discussed below. Full transcripts relating to task evaluation themes are given in Appendix L and general themes in Appendix M.

3.4.2.1 Themes relating to the evaluations of the tasks

Task 1: Free-form writing task about quality of life

With regard to component 1 - the free-form writing task about QoL – there was some, albeit limited, evidence to support the acceptability of this task:

“Within its limitations... it was adequate.” (female, age 81)

“It was helpful in seeing the information written down.” (female, age 59)

However, some participants expressed views that suggested both the information given and the writing task were too unstructured:

“I disliked the thought of writing an essay about myself.” (female, age 70)

“The information was not really new, but I needed something to guide my answer.” (male, age 70)

Suggestions for improvement included provision of specific headings or the provision of a checklist to facilitate the writing task:

“[It] needed to be divided into topics.” (female, age 70)

“It’s much easier to tick boxes. Headings would help but it’s difficult to do.”
(female, age 70)

It would be useful to have a checklist. It’s difficult otherwise, when you haven’t really thought about quality of life before.” (female, age 73)

Table 3.3 Tally of qualitative themes

Theme	<i>N</i> participants (Total <i>N</i> = 10)	<i>N</i> comments
Task Evaluation themes		
Free form writing task:		
Value of task (helpfulness / usefulness / adequacy)	5	6
Suggestions for improvement	4	8
1:1 feedback discussion		
Value of task (helpfulness / usefulness / adequacy)	9	17
Suggestions for improvement	0	0
WHOQOL graphs		
Value of task (helpfulness / usefulness / adequacy)	5	6
Suggestions for improvement	3	4
Sharing with others	6	15
Value of written instructions	5	6
Suggestions for written instructions	3	3
Goal elicitations and assessment		
Value of task (helpfulness / usefulness / adequacy)	5	7
Suggestions for improvement	3	6
Difficulty	5	10
Relevance	4	12
Age	4	8
General QoL Themes		
Personal interest	6	10
Understanding of definition	4	6
Novelty & curiosity	3	5
Catalyst for reflection	5	7
Cynicism / lack of interest	3	9
Dissociation construct and self	1	2
Adaptive strategies	4	6
Social support	2	2
Values and beliefs	1	1
Amusement / enjoyment	3	4
Age / ageing	3	7
Information	1	1
Finances	1	3

Task 2: Completion of WHOQOL-BREF and WHOQOL Importance questionnaires and provision of feedback.

Participants found that receiving feedback in the form of graphical representations of their self-ratings of QoL and the importance of its various aspects to be both interesting and valuable:

“Information very clear.” (female, age 59)

“Quite amusing to see my answers put into graph form.” (female, age 81)

“The graphs are helpful because they give an idea of my ambitions and achievements. Gives a focus.” (male, age 71)

“Interested to see how my answers were interpreted.” (female, age 70)

However, some comments suggested that the written instructions provided with the graphical summary profile could be made more succinct:

“It was rather obvious.” (male, age 70)

“Too wordy.” (female, age 70)

“They could have been more concise.” (female, age 73)

The additional component of exploring the graphs in a one-to-one discussion emerged as being particularly valued by participants:

“I preferred the one-to-one feedback because I like to be able to ask questions.”
(male, age 71)

“Being able to say something in response is nice.” (male, age 70)

“Asking leading questions is useful – exploring it in more depth. It’s good to explore.” (female, age 70)

“The interview clarified my own perspective of quality of life and necessity of growing old “gracefully”. (male, age 83)

Nevertheless for some participants this was felt to be unnecessary, as the graphical summary profile was perceived to be sufficient feedback alone.

“The explanations [were] all mostly self evident as far as this writer is concerned.” (male, age 83)

“Didn’t really need any help” (female, age 81)

“I find it far too introspective.” (male, age 75)

Participants who indicated they would look at the graphs again later stated that they would discuss them with friends and/or family and would do so for most aspects of the output. Intriguingly, in most of these cases participants suggested that this was not for their own benefit, but for that of the person with whom they would be discussed:

“My wife will probably be more interested than I am.” (male, age 75)

“Both my daughters are interested in my health and welfare.” (female, age 68)

“[For my friend] to understand the importance of my attitude to areas of my life.” (female, age 73)

Task 3: Goal elicitation and assessment

Participants gave both positive and negative feedback on the goal elicitation and assessment tasks. As indicated earlier, generation of personal goals was found to be difficult for a number of participants. Moreover, it was evident that a number of participants felt the concept of goals was inappropriate for older adults.

“The word goal was too formal” (female, age 75)

“... at my age (75+) I have no aims but to stay alive.” (male, age 75)

“I’m not sure if I really have any [goals]. [I] prefer to take one day at a time and rise to a challenge if it occurs.” (female, age 70)

“It’s more about not doing what I don’t want to do.” (male, age 75)

“Older adults guard against having goals because they may not be able to achieve them.” (female, age 70)

However, there was some limited acknowledgement that goals may still have relevance in later life.

“I need to consider setting goals in my life”. (female, age 73)

“[I] had to think about it. One has goals but does not always readily identify them.” (female, age 68)

“Could identify very short term goals.” (female, age 70)

“I really need to think about writing that book about all the stories I tell my grandchildren” (female, age 73)

Overall suggestions for improving this component included rephrasing the task, providing examples, and making the task more age-relevant. Despite the difficulties

expressed, two participants did state that the thinking about goals was, for them, the most important aspect of the study.

3.4.2.2 *General themes emerging from the qualitative data*

The full transcripts of comments relating to general themes are given in Appendix M. Recurring themes are given below.

Participants reflected on their personal interest in the general QoL information that had been provided in either in the written task or in terms of the feedback they received on their self-ratings of QoL. Many comments were optimistic in terms of finding consideration of their QoL positive and interesting:

“It is always good to reflect on one’s blessings.” (female, age 68)

“It was interesting to see your personal scale.” (female, age 59)

“It is always interesting to get feedback.” (female, age 68)

However four participants expressed a sense frustration at a perceived lack of understanding of the definition of QoL and a sense of dissociation between the concept and their own lives, for example:

“I think that “quality of life” needs more definition than self-centred goals and feelings. One’s general philosophy is the most important thing.” (female, age 81)

“I have great trouble with the concept, or the phrase, “the meaning of life””.
(male, age 70)

This was also clear in those comments suggesting that, rather than consider their QoL *per se*, some participants customarily employed short-term adaptive strategies in maintaining their wellbeing.

“[I] just get on with living” (female, age 81)

“It’s a personal thing – I cope with life by taking it one day at a time.”(female, age 70)

“What’s problematic I’ve solved, and what I can’t solve I accept.” (male, age 75)

The evidence also suggested that, for some, thinking about their QoL was not a familiar activity. There emerged a sense of novelty and curiosity in the task and comments also suggested recognition that taking part in the study had acted as a catalyst in terms of facilitating reflection on QoL:

“I’ve not analysed my quality of life before so it me think.” (female, age 70)

“Something I hadn’t considered before.” (female, age 73)

“It is always interesting to get feedback even if some of it is a little surprising.”(female, age 68)

“I don’t think about my quality of life usually.” (female, age 81)

“It has started me thinking of my quality of life at present.” (female, age 59)

As was noted in participants’ evaluations of the goal elicitation task, ageing was a theme that was commonly evidenced in their comments:

“I suppose my goal is to stay healthy and fit because I’ve got no-one to support me if I’m ill...When you’re younger, it’s different altogether.” (female, age 59)

“My only goal is to live to 80.” (male, age 75)

“I think as you get older you have less [sic] goals.” (female, age 59)

Not all participants were universally interested in the tasks or in the feedback. Some comments illustrated a degree of cynicism about the study:

“I understood what the research was trying to understand – although a trifle cynical in what it could produce!” (male, age 83)

“It’s about as interesting as a game of Scrabble. (I quite like Scrabble, but it’s not important.)” (female, age 81)

“It seems ungrateful I have a good quality of life but am not interested.” (male, age 75)

3.4.3 Summary of researcher observations

In considering the feasibility of administration of the tasks, this study revealed a number of issues that could provide potential enhancements to the methodological protocol. Firstly, the verbal protocol for the one-to-one feedback was too long, unnecessarily detailed and clumsy to verbalise. Secondly, some of the suggested probe questions were felt in practise to be too direct and unreasonably intrusive. Thirdly, both the one-to-one

feedback method and in the written instructions for reading the graphical summary profiles, needed to direct participants' attention more specifically to those facets where there was a clear difference between QoL and importance self-ratings. Finally, it was evident from the questions asked by some participants that definition of facets during the feedback process may have been helpful to fully facilitate their understanding.

3.5 Discussion

3.5.1 Main findings

The aim of this study was to develop the methodological aspects of a potential intervention to promote wellbeing. By evaluating the views of those taking part on the tasks they were asked to complete, both quantitatively and qualitatively, it sought to explore the novel components of the proposed intervention to in terms of their feasibility, face validity and acceptability to participants.

3.5.1.1 Consideration of quality of life

One of the findings that emerged most strongly from both the quantitative and qualitative data suggested that there was considerable personal interest in QoL as a concept and, in particular, in seeing and understanding one's own self-reported ratings. From the current literature it is clear that, although an increasing number of studies have successfully used the WHOQOL-BREF to examine QoL (Kalfoss, Low, & Molzahn, 2008; Lucas-Carrasco, Laidlaw, & Power, 2011; Lucas-Carrasco, Skevington, Gomez-Benito, Rejas, & March, 2011; Skevington & McCrate, 2012; Webster, Nicholas, Velacott, Cridland, & Fawcett, 2010) none has fed back the profile of results directly to participants on a one-to-one basis. Neither has this information been used to support individual's decision making about dimensions of their own QoL.

It was also evident that thinking about one's QoL appeared to be a novel task. Indeed for some participants there emerged the sense that this was something they were reluctant to do or that they considered unnecessary. Participants talked about more immediate, adaptive strategies for their daily lives – taking one day at a time for example.

Paradoxically, however, the data also suggested that the process of rating one's QoL was considered to be a catalyst for reflection. This qualitative evidence supports the view that enabling individuals to focus on their own QoL might provide a "window of opportunity" for planning new goals or for other re-assessment activities that may encourage adjustment to the challenges of life. Indeed in the context of chronic illness, as was mentioned in Chapter 1, Marshall et al. (2006) suggest the potential value of PROMs, such as QoL, lies especially enabling health professionals and patients together to set priorities despite the uncertainty of depleting health.

3.5.1.2 Evaluations of the tasks undertaken

The quantitative data suggested that reading a general passage about QoL was considered to be an interesting task. However, participants found the writing element of this component particularly difficult. By design, the instructions for the task were open-ended and offered no guidance as to what they should write. Participants cited this lack of direction as the source of their difficulty, which indicated that the task may have been too abstract. Their subsequent suggestions for improvement focused on the provision of a framework of headings by which their responses would be organised.

The graphical summary profiles, illustrating the self-ratings of QoL and importance ratings of the facets for each participant, were broadly appreciated. Numerous references cited individual's interest in the information, although the set of written instructions given to participants to assist them in interpreting the data were felt to be too long-winded and could have been presented more concisely. In line with these findings and with recommendations for task instructions it was decided that these instructions would be pragmatically abridged and retested in Study 2.

Support for the verbal feedback approach was largely evident. Reference was made to how some participants preferred this method to just following the written instructions, finding it easier to talk and discuss their graphical summary profile and thus being encouraged to explore the data in more depth. Others, however, were comfortable exploring the graphical summary profiles by themselves, and did not require additional help or support. In considering both these perspectives it may be that an inclination towards solitary reflection or participative discussion may be an individual preference.

This suggested that both approaches appeared to have validity and should be retained for further investigation in later studies.

An unexpected outcome of the research was the degree of difficulty that participants expressed in considering their personal goals. Despite limited recognition of the importance of having goals, responses to this task indicated that the methodology employed to identify goals was felt to be an onerous task and that participants commonly struggled to reconcile the concept of goals with their everyday lives. A sense of dissociation between setting goals and carrying out normal day-to-day activities was commonly apparent. This may be a particular feature of the sample population of older adults since many made reference to having fewer goals than when they were younger and that goal planning was no longer relevant. Indeed goal disengagement has been determined to be an adaptive strategy which buffers the negative effects of increasing functional limitations for older adults (Dunne, Wrosch, & Miller, 2011; Wrosch, Dunne, Scheier, & Schulz, 2006). Future investigations of goals with a wider sample of younger and older adults would be helpful in testing whether goal disengagement is a characteristic of ageing or whether it might similarly apply to other populations who have functional limitations e.g. people with mobility problems or difficulties with carrying out daily activities due to pain.

Regardless of whether goal disengagement was present, participants clearly found this task to be neither acceptable nor feasible. Indeed, the task itself may have been inappropriate and/or burdensome in its administration. It must also be considered that the very involvedness of this task may be problematic within the context of the research and that this would be the same for participants of any age. Further research to establish whether the difficulty lay with the convoluted nature of the task or with the particular sample in the present study, would inform potential future uses of this type of goal-setting activity.

Given the finding of difficulty with the goal tasks, it is plausible that the cognitive effort required in completing these goal-setting activities task may serve to mediate the effect of thinking about QoL. Originally intended to be an outcome measure in later studies (in terms of the nature of goals identified and the degree a success in their achievement), it seemed that the level of complexity and degree of participant deliberation required in the

task might be such that it could be considered an intervention in itself. It was therefore felt more appropriate to remove this element from the next phase of the study and to identify a more appropriate measure of the effect of individualised QoL feedback on personal goals.

3.5.1.3 Feasibility of administration

As well as giving insight into the acceptability of the tasks, this research highlighted a number of areas for reconsideration in terms of the feasibility of administration of a feedback intervention. From a researcher's perspective, the verbal protocol for the one-to-one feedback needed to remain standardised, but to be more concise and more directive in terms of signposting participants to where there were differences between their QoL and importance ratings. The written instructions were also deemed to need similar rewriting to focus attention towards these key indicators.

3.5.2 Study limitations

In reviewing the qualitative data, there was an evident reluctance to provide full and complete responses. Questions were frequently either missed out or single word answers given rather than full prose. It is plausible that the nature and number of the tasks and evaluations may have proved too burdensome and resulted in a consequent paucity of responses. The number of questions remaining incomplete supported this premise.

With regard to the sample used, it must be acknowledged as a limitation of this study that those who participated may not be fully representative of older adults. Participants in the study had a higher educational background than would normally be expected (80% had received some form of tertiary education) and future research should endeavour to recruit from a broader range of socio-economic groups. However, it could also be argued that, having received this level of education, this particular sample was appropriately equipped to provide a critical and rigorous evaluation of the study tasks.

In terms of analysis, the sample size was too small for a full statistical analysis. Descriptive statistics relating to evaluation scale responses were all that were feasible and even here means and standard deviations were viewed with considerable caution,

due to the small size of the sample. However, given the exploratory nature of this feasibility study and its specific aim to develop a methodology, not to measure experimental outcomes, the sample size was not considered inappropriate. Nevertheless, it was disappointing that six participants did not complete the goal elicitation tasks due to lack of time, or to their perception that the task was too onerous. Although this, in itself, provided a useful reflection on the tasks being requested of participants, a number of the evaluation questionnaires for this task were incomplete and statistical analysis of the data was not possible.

3.5.3 Recommended methodological modifications for the research programme

As a methodological development study, the findings of this phase of the research gave valuable insight into the acceptability and feasibility of methods to promote consideration of QoL and provide individualised feedback of QoL information. A number of possible modifications and improvements to the tasks were identified. These are summarised in Figure 3.10.

Refinements were identified which would further facilitate the consideration of QoL in both prose-based and questionnaire formats. Furthermore, findings identified refinements to a protocol for giving individualised WHOQOL questionnaire feedback using a new graphical summary profile. This was the first study to test this method with the WHOQOL and thus was unique and innovative.

Although the overall purpose of the study was to evaluate the tasks being undertaken, results also revealed interesting perspectives regarding the QoL perceptions of the participants and confirmed their interest in the topic. A key finding was that the data supported the hypothesis that thinking about QoL provides an opportunity for individuals to re-assess and re-evaluate their situation. Determining the process of thinking about QoL to be a novel but interesting experience for participants, the findings endorsed the underlying assertion of the thesis - that understanding one's own views on one's QoL has the potential act as a catalyst for the promotion of wellbeing.

Figure 3.10 Changes to the study methodology as a result of findings from the methodological development work

Component	Recommended changes	Purpose
Verbal feedback (script)	<p>Reduce detail of script</p> <p>*Make provision for flagging differences between importance and QoL within a facet, following new procedure:</p> <p>Flag facets with good (score 4-5) quality of life</p> <p>Flag facets with high (score 4-5) importance</p> <p>Discuss facets with poor(er) (score 1-3) QoL but high (score 4-5) importance</p> <p>Discuss facets with good (score 4-5) QoL and high (score 4-5) importance</p> <p>Discuss any other interesting facets</p> <p>Use questions to promote thinking, e.g. <i>What do you think about this? Is there anything that stands out for you? What do you think about this?</i></p>	<p>Ease of administration.; reduce repetition to maintain participants' interest</p> <p>Introduces more structure to the feedback</p> <p>Actively directs attention to key areas that may be most important to overall wellbeing</p> <p>Improve process of thinking about QoL</p>
Verbal feedback (script)	Consider providing facet definitions in accordance with WHOQOL rubric	Assists participants' understanding of QoL concept
Written instructions for r Graphs	<p>Incorporate instructions to focus on facets as above*</p> <p>Include questions to promote thinking as above*</p>	Directs attention to key areas that may be most important overall wellbeing
Free-form writing task	Re-write definition of QoL to make it more "user-friendly"	Assists participants' understanding of QoL concept
Free-form writing task	Insert headings into written information and to structure writing task based on WHOQOL 6 domain format: physical, psychological, social relationships, environment, independence and spiritual.	Assists ease of completion of task and promotion of consideration of QoL aspects
Goal elicitation and assessment task	Remove task from remaining studies. (It may, however, be useful to investigate this approach separately in future research.)	Reduce risk of confounding results. Ease participant burden.
WHOQOL Importance Questionnaire	Compress spacing on questionnaire to limit physical number of pages.	Reduce perceived participant burden
All aspects	Make it clear, in all verbal and written instructions, that there are no right or wrong answers.	Increase reliability of results (reduce risk of participants responses being biased by social desirability.)

Although it was considered outside the remit of this thesis, this study also revealed clear potential for future investigation into the challenges of ageing and principally with regard to the relevance of goals and goal setting in later life. Whilst a specific module of the WHOQOL instrument has been developed for use with older adults (Power, Quinn, & Schmidt, 2005), further work could be valuable in relating this to an understanding of how goals are perceived by this population.

3.5.4 Conclusion

Study 1 provided valuable methodological guidance to inform and amend the design of the next phases of the research. The next two chapters in this thesis describe how the refined methodology was applied in answering the overall research questions of the research programme. Chapter 4 provides an account of a pilot study to investigate the effect of thinking about QoL on subsequent wellbeing. Chapter 5 examines the effect on QoL of providing individualised structured QoL feedback of WHOQOL-BREF and WHOQOL Importance scores. Later Chapter 7 returns to the question of individuals' use of QoL information after receiving individualised feedback.

CHAPTER 4. STUDY 2: WHAT ARE THE EFFECTS OF THINKING ABOUT QUALITY OF LIFE?

4.1 Introduction

Chapter 2 presented the underlying aim of this research programme: to develop the basis of a self-management tool, by feeding back QoL information at a person-centred level, to promote wellbeing. To this end, Study 1 had provided considerable value in terms of offering amendments to the methodologies used, in order to increase their acceptability and feasibility. From this data, protocols both for promoting thinking about QoL and for the provision of feedback on QoL self-judgements were able to be refined.

The next phase of the research aimed to examine the effects of these refined methodologies on subsequent wellbeing. However, in considering the design of the next study, it became apparent that attempting to investigate the effect of *both* the thinking processes and feedback processes *together* in a subsequent study would raise questions of validity. In such a study it would be impossible to identify exactly what might be the active component – the cognitive process of thinking about QoL *or* the provision of feedback. It was therefore decided that the next study should investigate the first element separately i.e. to measure solely the effects of the process of thinking about QoL. Had it been possible, the exclusive effects of the feedback process would have also been similarly isolated in another investigation. However, as this process inherently requires that participants think about their QoL in order to elicit the self-ratings to discuss in the feedback, this was not a viable option. Therefore this chapter is concerned exclusively with measuring the effects on wellbeing resulting from reflecting upon one's own QoL without feedback.

Reviewing the literature regarding measurement of psychological processes highlighted a growing concern with the effects of the process of completing self-report assessments, sometimes referred to as “measurement reactivity” (French & Sutton, 2010; French & Sutton, 2011). This is relevant to Study 2 as completing a QoL instrument or reflecting

on one's QoL may conceivably also be subject to these effects. An appraisal of the current literature was thus considered to be highly relevant and is provided below, to further support the rationale for Study 2.

It is plausible to conceive that participants in psychological research may not necessarily behave in their normal way if they are aware that they are taking part in some form of study or assessment. Indeed it has been recognised for some considerable time that intentions, beliefs and attitudes may be created by the very act of measurement if the measured constructs do not already exist in long term memory (Feldman & Lynch, 1988). For this reason “unobtrusive” measurement has often been advocated in psychological research. However, in practice, this is very difficult to achieve when measuring constructs such as beliefs, attitudes and emotions, where explicit self-report measures are frequently utilised. Although the possibility that the mere act of measurement can bring about change for those who complete them was noticed in psychological research as long ago as the 1950s (Windle, 1954), it has nevertheless been recently asserted that researchers in psychology are inclined to assume that completion of self-report questionnaires, in itself, has no subsequent effect on feeling, thoughts or behaviours (French & Sutton, 2011).

However, a growing body of evidence suggests that the process of psychological measurement is indeed “reactive”. In a review article, French and Sutton (2010) concluded that considerable evidence exists to suggest that individuals who complete psychological measures are affected in some way in terms of their subsequent behaviour, emotions or cognitions. They further recommended that due consideration of reactivity effects should be included in any psychological research and that researchers should seek to employ designs that will reduce the potential for bias.

Several studies have found that measurement procedures altered subsequent cognitions and behaviours. In terms of initiating behaviour change, for example, a meta-analysis of interventions to promote physical activity found that merely asking participants to wear pedometers encouraged self-monitoring, and was, in itself, an effective behaviour change technique (Michie, Abraham, Whittington, McAteer, & Gupta, 2009). Other studies have similarly shown that pedometer wearing leads to an increase in self-

reported physical activity (Bravata Dena et al., 2007; Spence, Burgess, Rodgers, & Murray, 2009; van Sluijs, van Poppel, Twisk, & van Mechelen, 2006).

In reviewing the effects of instrument completion on emotion, French and Sutton (2010) pointed out that there are few options but to measure emotional reactions with the explicit consent of the participant. However, this introduces an inherent bias in that people who are more distressed may be less likely to return postal questionnaires and that differential drop out may further affect the results of the study. A number of studies have found evidence of reactivity in terms of emotions from questionnaire completion, although the direction of reported effects is contradictory. Some findings suggest that higher anxiety or depression scores can result (Johnston, 1999; Lister, Rode, Farmer, & Salkovskis, 2002). Conversely, a study by Sharpe and Gilbert (1998) found reductions in negative emotions between repetitions of a number of measures including the Beck Depression Inventory and the Profile of Mood States. Given that most studies have no baseline measure of emotion before participation, it is unclear whether effects are due to accessing negative thoughts (in the case of increasing anxiety or depression), or due to the beneficial effects of emotional expression in cases where negative emotions may be reduced (a mechanism proposed by Pennebaker (1997) as a means of overcoming trauma).

A critique by Ogden (2003), postulated that the use of questionnaires designed to assess cognitions may instead create the very cognitions they set out to measure. Ogden pointed to evidence from “think aloud” studies which have found that the questionnaire itself can be a catalyst for a new thought that the participant did not previously possess (Darker & French, 2009). Similarly, when encountering difficult questions, normative beliefs have been drawn upon and re-presented as participants’ individual cognitions (Darker & French, 2009; French, Cooke, McLean, Williams, & Sutton, 2007) .

However, there is some evidence to suggest that reactivity effects do not always occur. The study by Sharpe and Gilbert (1998), as cited earlier, whilst finding effects in some measures of negative emotion, also found no differences in repeated administrations of the PANAS Negative Affect Scale. They concluded that further research was required in order to understand the contradictory evidence found for different instruments. Similarly, a study employing a diabetes questionnaire, observed no discernible effects on

emotion (anxiety) compared with people who had not completed the measure (French et al., 2009). In trying to explain the apparent contradiction in this latter study, French and Sutton (2011) postulated that the absence of effect may have been due to questionnaire having been administered by post. They argued that in this method of administration, factors such as the absence of an interviewer; the fact that respondents have more time to complete the questionnaire; and the perceived ease of withdrawal from the study may have resulted in fewer “reactive” effects.

Specific literature about the effects of QoL assessment is sparse. However, a frequently cited study by Velikova et al (2004), which measured the QoL over time of cancer patients in routine oncology practice, found mixed effects for patient outcomes. Their methodology employed use of touch-screen QoL questionnaires to administer a cancer specific QoL questionnaire (the European Organisation for Research and Treatment of Cancer-Core Quality of Life Questionnaire – EORTC QLQ-C30) and the Hospital Anxiety and Depression Scale (HADS) as intervention components prior to clinic appointments, with feedback provided to the clinical staff. Patient outcomes were measured using the Functional Assessment of Cancer-General (FACT-G) containing four subscales: physical well-being, social or family well-being, emotional well-being and functional well-being. The study was primarily designed to investigate the effects of QoL assessment on patient-physician communication. However, it included a comparison of the scores of those who completed the intervention questionnaires in an attention-control group, with those of a control group who did not complete any measures. Result showed no differential in positive effects on the emotional wellbeing, or social and family wellbeing subscales between these two groups, however, between group differences were found for general QoL and the physical wellbeing and functional wellbeing subscales (although the latter was only approaching statistical significance). Velikova and colleagues concluded that completion of the questionnaires may have led to these observed differences in patient well-being.

A further level of complexity is introduced when one considers whether it is the completion of a questionnaire that may or may not bring about a measurement effect or the mere receipt of the questionnaire that may instigate reactivity. A recent study into the impact of questionnaire completion on subsequent blood donation behaviour investigated this question by comparing participants who completed a questionnaire with

those who received but did not complete it (Godin, Sheeran, Conner, & Germain, 2008). Findings suggested that completion of the questionnaire was a necessary prerequisite for subsequent generation of measurement effects. Receipt alone was not sufficient to bring about change.

In all of the cited studies, whilst trying to isolate reactivity, it is nevertheless possible that mere inclusion in the research may have brought about some measurement effect. In being recruited to an overt QoL study, for example, all participants may consciously or unconsciously attend to aspects of their QoL, whether or not they are asked to complete a formal structured instrument or other form of assessment. This problem is not unique to QoL research but, as was shown earlier, is a potential issue for psychological research more generally and one which is difficult to overcome.

The first aim of Study 2 therefore was to conduct a “proof of principle” pilot study to investigate whether the cognitive process of thinking about QoL could, in itself, bring about changes in self-judgements of QoL and other relevant outcomes. Within this, a second aim was to determine whether there would be any differential effect between participants who were merely asked to think and write their thoughts about QoL in an unstructured format and those who completed a structured questionnaire.

Chapter 1 of this thesis discussed the key concepts that are elemental within SRT (Carver & Scheier, 1998) and highlighted the correspondence between the theory and the WHOQOL (1995) definition of QoL. Recognising one’s current QoL was presented as fulfilling the input value of the loop (i.e. identification of a current state). The influence of the feedback loop on emotions was also explicated as was the importance of identifying the discrepancy between current and ideal states. In this context, it was decided to measure current QoL, mood and QoL-related goal orientation as these should indicate what effect (if any) the act of thinking about QoL might have on the feedback loop. Standardised measures of these constructs were thus selected for Study 2 and will be described in more detail in section 4.2. Whilst dispositional optimism/pessimism was also discussed in Chapter 1 in relation to SRT, this represents an enduring personality trait, rather than a more transient “state”. As such, it was decided inappropriate to measure this construct in the present research, as it would be expected to be less sensitive to intervention or experience effects.

The primary research question for this study was:

What effect does the act of thinking about one's own QoL have on an individual's later assessment of his/her QoL, mood and QoL-related goal orientation?

The secondary research question was:

Is there any differential effect in QoL, mood and QoL-related goal orientation between thinking about QoL in a structured or semi/unstructured format?

4.1.1 Hypotheses

It was hypothesised that the process of thinking about QoL information would affect individual's later judgements about their QoL, on their emotional state, and on their QoL-related goal orientation. More specifically:

1. Thinking about one's QoL will affect subsequent post-test measures of self-rated health status, mood and QoL-related goal orientation in the short term.
2. Thinking about one's own QoL in a structured format will have a stronger effect than in a semi/unstructured format.

4.2 Method

4.2.1 Study design

As mentioned earlier, the findings of the previous methodological development study described in Chapter 3 recommended a number of amendments to the original methodology. These were incorporated into the methodology adopted for this study.

This mixed methods study used a pre and post-test design (times 1 and 2) plus a post study follow-up evaluation of change (time 3). All measures were administered in paper format. The primary quantitative outcome measures were health-related QoL; mood; and QoL-related goal orientation. The post-study evaluation of change questionnaire

collected both quantitative and qualitative data. Using transition questions, in the form of Likert scales, to capture self-reported changes, subjective reflections on post study changes were also elicited to further explore the experiences individuals reported and their reflections on taking part in the study.

The study had three experimental conditions:

Condition 1 – Structured task: Completion of the WHOQOL-BREF questionnaire (see Chapter 3, Figure 3.3).

Condition 2 – Semi-structured task¹: Reading a passage of information about QoL and describing one's own QoL in relation to four headings reflecting each domain of the WHOQOL-BREF, plus responding to an open question about anything else that might affect QoL. Answers were free-form within each heading (see Figure 4.1).

Condition 3 – Unstructured task²: Reading a passage of information about QoL, and describing one's own QoL, with no further guidance or instruction (see Figure 4.2).


4.2.2 Sample inclusion and exclusion

Study 1 had found that results from a sample population of older adults might not be generalisable to other age groups, particularly in relation to attitudes towards goals. It was therefore decided that the pilot sample population for Study 2 should be more representative of the adult population of the UK in terms of age. Sampling was consequently purposive and a quota sampling strategy was used to achieve a heterogeneous sample of adults with regard to age, reflecting balance between two age bands: below and above 50 years of age.


¹ This design of this condition was informed by the findings of Study 1, i.e. it was more concise than that used before and sought directly to promote a clear understanding of QoL as a concept. Response headings were provided to promote ease of completion.

² The passage of information provided in this task also was informed by the findings of Study 1, in the same way as for Condition 2, but with the exclusion of response headings in order to retain it as an “unstructured” task.

Figure 4.1 Semi-structured writing task



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To be completed by the researcher:

Participant reference:

Quality of Life

The term "quality" can be defined as a grade of goodness. "Quality of Life" therefore, is about the goodness of life. Sometimes quality of life is considered to relate only to physical health or mental health, but it can really include all those aspects of life that make up our whole sense of well-being.

For example, people can think about quality of life in terms of:

- having a positive psychological outlook and emotional well being
- having good physical and mental health
- having the physical ability to do the things they want to do
- having good relationships with friends and family
- participating in social activities and recreation
- living in a safe neighbourhood with good facilities and services
- having enough money
- being able to be independent

So how we assess our quality of life very much depends on the circumstances or situations in which we find ourselves as well as whether we feel generally fit, healthy and able.

It is also suggested that quality of life is related to the expectations we have for ourselves – about whether we have achieved what we had thought we might, and about whether we see ourselves in a way we might have hoped for. These expectations are to some extent based on the experiences and events we have faced in life. These experiences put our

1



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To be completed by the researcher:

Participant reference:

views of ourselves into a sort of context and help us make judgements about what matters to us and whether we then consider our quality of life to be good or poor.

There are many ways of measuring quality of life, but they all depend on people making their own judgements. No-one can tell you how you think about your quality of life. Other people can make estimates for you, but you are the only one who really knows how you feel about your life.

When researchers look at quality of life they are often interested in how satisfied people are with aspects of their lives as it is this that really matters. For example, two people may find it very difficult to sleep properly at night. For one of them this may be a problem because it severely affects their energy levels. For the other, however, they cope very well on limited sleep, it doesn't affect their activities during the day, and so they are still very satisfied with this aspect of their life.





We would like you to think about your satisfaction with aspects of your life. In your own words, please complete this form by describing your quality of life for each aspect listed. Please try to explain your answers as fully as you can. You can use the blank space on the final page if you need more room.

*Example: In relation to my **physical health**, my quality of life is:*
good because I have plenty of energy and no aches and pains. I can get around easily to do the things I want to do.

2

Please turn to page 3

Figure 4.1 Semi-structured writing task cont.

<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="text-align: center;">  <p>WHO Field Centre <i>for the study of quality of life</i></p> </div> <div style="text-align: center;">  <p>UNIVERSITY OF BATH</p> </div> <div style="border: 1px solid black; padding: 2px; font-size: 0.8em;"> <p><i>To be completed by the researcher:</i></p> <p>Participant reference:</p> </div> </div> <p style="margin-top: 20px;">In relation to my physical health, my quality of life is:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <p>In relation to my psychological health, my quality of life is:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <p>In relation to my social relationships, my quality of life is:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <p>In relation to my environment, my quality of life is:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <p style="text-align: right; margin-top: 10px;">Please turn over →</p> <p style="text-align: center; margin-top: 20px;">3</p>	<div style="display: flex; justify-content: space-between; align-items: center;"> <div style="text-align: center;">  <p>WHO Field Centre <i>for the study of quality of life</i></p> </div> <div style="text-align: center;">  <p>UNIVERSITY OF BATH</p> </div> <div style="border: 1px solid black; padding: 2px; font-size: 0.8em;"> <p><i>To be completed by the researcher:</i></p> <p>Participant reference:</p> </div> </div> <p style="margin-top: 20px;">Other things that affect my quality of life are:</p> <hr/> <hr/> <hr/> <hr/> <hr/> <p style="text-align: center; margin-top: 20px;"><i>Please use this space for any further comments:</i></p> <p style="text-align: center; margin-top: 40px;">Thank you for your help.</p> <p style="text-align: center; margin-top: 20px;">4</p>
---	--

80

12

Only adults (aged 18 or over) were included in the study and they were required to give their full informed consent to taking part. Participants were also asked to complete the questionnaires independently therefore they needed to be literate, able to understand the information they were given and able to communicate sufficiently well in English. Literacy and understanding was assessed from the data they provided including responses and written passages and responses to open-ended questions. Ethical approval for the study was granted by the University of Bath, Department of Psychology Research Ethics Committee.

4.2.3 Procedure

Older adults (aged 50+) were targeted via the local U3A through re-contacting, by letter, those members who had volunteered to take part in the previously study, but who had not been recruited at that time. Letters were sent to the interested potential participants from the U3A inviting them to leave their contact details on a voicemail if they wished to take part. An additional community sample of adults was recruited through local advertising flyers (see Appendix N) and snowballing from those already recruited.

On recruitment to the study participants were randomly allocated to one of three experimental conditions using allocations generated by an internet randomisation tool - www.randomizer.org. All participants were sent a letter containing study documents – participant information sheet, consent form, questionnaire booklets (T1 and T2) and the task sheets. The participant information sheet gave further information including the purpose and nature of the study, the tasks involved, the options for withdrawal or complaint, and a summary of how the data would be handled and used. The covering letter requested that participants read the participant information sheet, complete the consent form and then complete the documents in a specific order: T1 questionnaires, task sheet, T2 questionnaires. Participants were provided with pre-paid, addressed envelopes, for the return of completed documents. After receipt of these documents, participants were sent a post study evaluation questionnaire (T3). The participant information sheet, consent form and covering letters, as sent to participants, are given in Appendix O.

4.2.4 Measures

The WHOQOL-BREF was used in condition 1 (structured task) to facilitate individuals' reflection on their QoL. As such, it was considered appropriate to use a different QoL instrument to measure health-related QoL as an outcome. The EQ-5D (The EuroQoL Group, 1990) was therefore selected as the primary QoL outcome measure. The National Institute for Clinical Excellence (NICE) recommends the EQ-5D as the preferred measure of health-related QoL in adults (National Institute for Health and Clinical Excellence, 2008). It was therefore believed likely to be familiar to healthcare professionals and thus to be an appropriate choice for research that might have future applications in National Health Service settings. Furthermore, the EQ-5D was designed for use in evaluative studies and allows comparison across patient groups (Carr, 2003). The EQ-5D is also considered easy to use and is asserted to be one of the most widely used utility measures in medicine (Lillegraven & Kvien, 2007). It captures self-ratings of health status in a descriptive system according to 5 dimensions (mobility, self-care, usual activity, pain/discomfort and anxiety/depression) and was originally developed as a 3-level system indicating no problems, moderate problems and extreme problems. The EQ-5D also includes a 100 point visual analogue scale (VAS) which is designed to allow participants to identify their overall health state (where 0 = worst imaginable health and 100 = best imaginable health).

Despite demonstrating strong psychometric properties in general, the EQ-5D is, however, considered by some to have a restricted ability to discriminate small to moderate differences between individuals or within individuals over time and to be subject to ceiling effects (Macran, Weatherly, & Kind, 2003; A. W. Wu et al., 2002). This has particularly been found in when there are lower levels of perceived ill health (Myers & Wilks, 1999). Accordingly a 5-level "experimental" version was more recently developed by Janssen, Birnie and Bonsel (2008) in order to increase the measure's discriminatory power. This 5-level version was used in this study with the original VAS retained (see Figure 4.3).

The Positive and Negative Affect Schedule (PANAS) (Watson, Clark, & Tellegen, 1988) questionnaire was selected to measure changes in affect. Designed to measure positive and negative affect independently this instrument consists of two ten-item mood scales which have been determined to be internally consistent, largely uncorrelated and

Figure 4.3 5L EQ-5D (Janssen et al., 2008)

To be completed by the researcher:
Participant reference:

5L EQ-5D

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility
I have no problems in walking about
I have mild problems in walking about
I have some problems in walking about
I have many problems in walking about
I am unable to walk about

☐
☐
☐
☐
☐

Self-Care
I have no problems with self-care
I have mild problems washing or dressing myself
I have some problems washing or dressing myself
I have many problems washing or dressing myself
I am unable to wash or dress myself

☐
☐
☐
☐
☐

Usual Activities (e.g. work, study, housework, family or leisure activities)
I have no problems with performing my usual activities
I have mild problems with performing my usual activities
I have some problems with performing my usual activities
I have many problems with performing my usual activities
I am unable to perform my usual activities

☐
☐
☐
☐
☐

Pain/Discomfort
I have no pain or discomfort
I have mild pain or discomfort
I have moderate pain or discomfort
I have severe pain or discomfort
I have extreme pain or discomfort

☐
☐
☐
☐
☐

Anxiety/Depression
I am not anxious or depressed
I am a little anxious or depressed
I am moderately anxious or depressed
I am very anxious or depressed
I am extremely anxious or depressed

☐
☐
☐
☐
☐

To be completed by the researcher:
Participant reference:

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today

Your own health state today

Thank you

Best imaginable health state

100
90
80
70
60
50
40
30
20
10
0
Worst imaginable health state

83

stable (Watson et al., 1988). Items are rated from 1 to 5 and summed to provide a total score for positive affect and a total score for negative affect, each of which can range from a minimum of 10 to a maximum of 50.

The PANAS has been determined to be a reliable and valid measure in the general UK population (Crawford & Henry, 2004) and in both clinical and non-clinical populations (Crawford & Henry, 2004; Ostir, Smith, Smith, & Ottenbacher, 2005; Terracciano, McCrae, & Costa, 2003). Mood has been demonstrated to be closely aligned with QoL (Ekici, Ekici, Kara, Keles, & Kocyigit, 2006; Friedman et al., 2005; Skevington & Wright, 2001) and as such it was felt that the PANAS was an appropriate measure in the context of thinking about QoL. A copy of the PANAS is given in Figure 4.4.

The Goal-Oriented Subjective Status scale (GOSS) was developed by Dibb and Yardley and used in two studies examining adjustment in chronic illness (Dibb & Yardley, 2006; Yardley & Dibb, 2007). As a framework, they referred to the SRT model in which Carver & Scheier had suggested that the ideal and actual rates of progression towards goals has affective consequences (Carver & Scheier, 1990, 2000). They proposed the GOSS scale as a measure of adjustment based on people's perceptions of how quickly they were moving towards or away from their goals. The scale contains 5 domains they considered important to QoL – family and relationships; health; work and finances; social life and activities; and spirituality and beliefs. Each item is scored from -3 to +3 and can be summed to produce a total score ranging from -15 to +15. Dibb and Yardley postulated that the GOSS thus provides an explicit measure of the effect of changes in goal standards that might complement measures of subjective status. Their work demonstrated the GOSS scale to have good internal consistency (Cronbach's $\alpha \geq 0.8$) and to be meaningfully related to, but distinct from another widely used health and functional status measure, the short form SF-36 (Jenkinson, Wright, & Coulter, 1993) (Dibb & Yardley, 2006; Yardley & Dibb, 2007). It was therefore determined to be a valuable measure to include in this research. However, for the purposes of this programme of research, the original GOSS scale was adapted to reflect the original 6 domains of QoL identified by the WHOQOL Group in the development of the WHOQOL-100 questionnaire (The WHOQOL Group, 1995). To do this an additional domain was added and some of the item wording was changed to more explicitly relate the measure to "ideal QoL". The resulting "GOSS-Q" scale is shown in Figure 4.5.

Figure 4.4 PANAS instrument (Watson et al., 1988)

To be completed by the researcher:
Participant reference:

POSITIVE AND NEGATIVE AFFECT SCHEDULE

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the appropriate answer for each word. Indicate to what extent you feel this way **right now, that is, at the present moment.**

	very slightly or not at all	a little	moderately	quite a bit	extremely
interested	1	2	3	4	5
distressed	1	2	3	4	5
excited	1	2	3	4	5
upset	1	2	3	4	5
strong	1	2	3	4	5
guilty	1	2	3	4	5
scared	1	2	3	4	5
hostile	1	2	3	4	5
enthusiastic	1	2	3	4	5
proud	1	2	3	4	5
irritable	1	2	3	4	5
alert	1	2	3	4	5
ashamed	1	2	3	4	5
inspired	1	2	3	4	5
nervous	1	2	3	4	5
determined	1	2	3	4	5
attentive	1	2	3	4	5
jittery	1	2	3	4	5
active	1	2	3	4	5
afraid	1	2	3	4	5

Thank you

As can be seen, the QoL dimensions of this measure are physical, psychological, social, environmental, independence and spirituality, religiousness and personal beliefs. As in the original GOSS version, respondents are asked to provide subjective judgements of how quickly they feel they were moving away from or towards their ideal state for each of the QoL dimensions. For the purposes of this and subsequent studies in the thesis, each item in the GOSS-Q was scored from 1 – 7, where 1 = moving very quickly away and 7 = moving very quickly towards. The total of scores thus ranged from 6 – 42³.

Evaluation of change data were elicited through a questionnaire completed at the end of the study (see Figure 4.6). By including transition questions assessing change, it was intended that a more accurate assessment of perceived changes might be obtained and that this might provide a benchmark against which to view any statistical changes detected. A combination of Likert scales and open-ended response questions were used to investigate individuals' experiences of the tasks, including their subjective views on how they felt their participation in the study had affected the way in which they thought about their QoL. They were also asked to record how much taking part had brought about changes in their QoL (with response options from “much worse” to “much better”, including “about the same”). They were asked whether they way they thought about their QoL had changed, and whether they had perceived any changes in their plans or expectations for the future, or in their mental or physical health. These dimensions were chosen to reflect possible outcomes of the process of thinking about QoL as well as changes related to the other constructs being measured (affect, health and functional status, and QoL-related goal orientation).

Finally, participants were asked to rate how helpful they thought their experience of the study would be in the short (1-2 weeks), medium (3 months) and long terms (more than 3 months). This was included to elicit data regarding acceptability and feasibility of the study in order to inform subsequent protocols. Substantiating comments were requested

³ The purpose of this scoring system was to remove negative numbers from the dataset but, more importantly, facilitated the analysis of data captured in electronic survey form, as used in Study 3 of the thesis (see Chapter 5).

throughout the questionnaire in order to support the quantitative data and to elicit any additional insights on the process or experience of reflecting on QoL.

Figure 4.5 GOSS-Q instrument

To be completed by the researcher: Participant reference:						
The Goal-Oriented Subjective Status Scale for Quality of Life (GOSS-Q)						
<p>Please look at the six areas of quality of life listed below and try to imagine <i>your</i> ideal situation in each area. Then tick one box to show which is most appropriate for you TODAY. Please answer all the questions.</p>						
<p>1) How quickly do you feel that you are moving towards or away from your ideal physical quality of life?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards
<p>2) How quickly do you feel that you are moving towards or away from your ideal psychological quality of life?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards
<p>3) How quickly do you feel that you are moving towards or away from your ideal social quality of life?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards
<p>4) How quickly do you feel that you are moving towards or away from your ideal environmental quality of life?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards
<p>5) How quickly do you feel that you are moving towards or away from your ideal quality of life with regard to your level of independence?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards
<p>6) How quickly do you feel that you are moving towards or away from your ideal quality of life with regard to your spirituality, religiousness, and personal beliefs?</p>						
<input type="checkbox"/> very quickly away	<input type="checkbox"/> quite quickly away	<input type="checkbox"/> slowly away	<input type="checkbox"/> not moving at all	<input type="checkbox"/> slowly toward my ideal	<input type="checkbox"/> quite quickly towards	<input type="checkbox"/> very quickly towards

Figure 4.6 Post-study evaluation of change questionnaire

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To be completed by the researcher:
Participant reference:

Quality of life and wellbeing - Follow up questionnaire

This questionnaire asks how you feel about changes that may have happened for you whilst taking part in this study. Please answer all the questions as fully as you can. There is room back page of the questionnaire if you need more space for your answers.

1. In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers the second time? (Please tick one box)

Yes ☐
No ☐

If Yes, what changed? (Please describe)

2. How much has your quality of life changed as a result of taking part in this study? (Please circle one number.) My quality of life is now....

Much worse	Worse	A little worse	About the same	A little better	Better	Much better
1	2	3	4	5	6	7

If your quality of life **has** changed at all, in what ways has it done so? Please describe in your own words.

Please turn over

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To be completed by the researcher:
Participant reference:

3. How much has participating in this study **changed the way you think about your quality of life?** (Please circle one number.) The way I think about my quality of life has...

Not changed at all	Changed a little	Changed a fair amount	Changed a lot	Changed completely
1	2	3	4	5

If the way you think about your quality of life **HAS** changed, in what ways has it done so? Please describe in your own words.

4. How much has thinking about your quality of life changed your **plans or expectations for the future?** (Please circle one number.) My plans or expectations for the future have ...

Not changed at all	Changed a little	Changed a fair amount	Changed a lot	Changed completely
1	2	3	4	5

If your plans or expectations for the future have changed, in what ways have they done so? Please describe in your own words.

Please turn to page 3

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To be completed by the researcher:
Participant reference:

5. How much has thinking about your quality of life changed your **physical health?** (Please circle one number.) My physical health has ...

Not changed at all	Changed a little	Changed a fair amount	Changed a lot	Changed completely
1	2	3	4	5

If your physical health has changed, in what ways has it done so? Please describe in your own words.

6. How much has thinking about your quality of life changed your **mental health?** (Please circle one number.) My mental health has ...

Not changed at all	Changed a little	Changed a fair amount	Changed a lot	Changed completely
1	2	3	4	5

If your mental health has changed, in what ways have it done so? Please describe in your own words.

Please turn over

WHO Field Centre
for the study of quality of life

UNIVERSITY OF BATH

To be completed by the researcher:
Participant reference:

7. How helpful will your experience of this study be to you in the future?

a. Firstly in the short term (in the next two weeks):

Very unhelpful	Mostly unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

b. Now thinking about the medium term (in the next three months)

Very unhelpful	Mostly unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

c. Finally thinking about the long term (more than three months)

Very unhelpful	Mostly unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

8. Is there anything else you would like to tell me that has not already been covered in this questionnaire?

Thank you for your help.

4.2.5 Data preparation

Along with the EQ-5D VAS scores, total scores were calculated for each participant for the PANAS positive affect items, the PANAS negative affect items and for the total of responses to the GOSS-Q items. Index values generated from the EQ-5D scores were not included in statistical analyses as the value sets allowing conversion of the EQ-5D-

5L descriptive system into a single index score had not been published at the time of the study. However, health profiles of participants' responses were generated from the descriptive system.

Prior to analyses, the main outcome variables were examined for accuracy of data entry, missing values and extreme scores (Tabachnick & Fidell, 2001). Examination of standardised scores for values within the EQ-5D VAS, PANAS and GOSS-Q scales, revealed two extreme scores, one in the EQ-5D VAS at T1 and the other in the PANAS negative affect score at T1. These extreme scores related to two different participants and were marginally outside the range $z = \pm 3.29$. Following the guidance of Dancey & Reidy (2004) and of Tabachnick & Fidell (2001), the raw scores to which these related were adjusted to one unit more/less than the next lowest/highest case.

Normality indices indicate acceptable levels of skewness and kurtosis (i.e. within the ± 1 range recommended range by Hair, Anderson, Tatham and Blacke (1999)) for most variables. However, skewness and kurtosis for the total values of the Negative Affect scale of the PANAS were problematic. Skewness values were 1.6 at T1 and 1.8 at T2. Kurtosis values were 1.6 at T1 and 2.3 at T2. Following the guidance of Field (2005) logarithmic, square root and reciprocal transformations were applied. The reciprocal transformation had the effect of bringing the kurtosis of the data within the acceptable range and reducing the skewness to only marginally beyond ± 1 . These data were subsequently retained.

4.2.6 Data analysis

Statistical examination of the data was conducted using SPSS v18.0. Health profile scores were derived from the EQ-5D descriptive system data to reflect patterns within the overall sample. Statistical analysis commenced with descriptive statistics and a mixed factorial MANOVA to explore the variance in scores over time and between conditions. Time was entered as the within-subjects factor and condition (questionnaire or descriptive prose) as the between-subjects factor. In order to ensure that the cumulative Type 1 error remained below .05 for multiple comparisons, Bonferroni corrections were applied (Field, 2005). As the repeated measures study contained only two levels: T1 and T2, sphericity was not a concern. Nevertheless, Greenhouse-Geisser

adjustments were used throughout the ANOVA analyses. These have the effect of producing valid F -ratios should the assumptions of sphericity have been violated and are thus deemed to be more conservative than alternative tests (Dancey & Reidy, 2004).

Data from the Likert scales in the post-study evaluation of change questionnaires (T3) were analysed by calculating the percentages in each response category. Additionally the data provided by ratings of change were dichotomised to identify participants where there had been no change reported and those who had reported change their responses to one or more of the questions. These data were then able to be examined further statistically using independent t tests and MANOVA. In the exploratory t tests, homogeneity of variance was assumed, except where Levene's test indicated that this was not tenable. In these cases the "equal variances not assumed" t test result was consequently accepted (Kinnear & Gray, 2010). In all t tests 2-tailed p values were used as, for most analyses, direction of effect had not been assumed *a priori*.

Qualitative data were also gathered in the post-study evaluation of change questionnaire. Results were not extensive, so full thematic analysis was not undertaken. However, comments were collected to provide additional insight into participants' appraisals and to support the quantitative data.

4.3 Results

Twenty five participants were recruited with an age range from 25 to 80 years. One other had been recruited, but withdrew from the study after completion of the T1 questionnaires, citing lack of time to participate further. Within the remaining sample, 56% were in the older adults' band (i.e. aged 50+), the average age of the sample was 52 years and the sample comprised 4 males and 21 females. Additional socio-demographic data were collected from all participants including: marital status, health status, health problems currently experienced, ethnic origin, education level, living arrangements and current or previous occupation. This information was retained for investigative purposes, and is given in Table 4.1, but was not considered relevant in terms of inclusion or exclusion criteria.

Table 4.1 Demographic characteristics of Study 2 participants

		<i>N</i>
Highest Education	Secondary School	3
	College or University	10
	Post-graduate	11
Marital Status	Single	7
	Married	9
	Partnered (not married)	4
	Separated/divorced	1
	Widowed	3
Living arrangements	Living alone	5
	Living with partner/spouse/family	13
	Living with housemates/flatmates	6
Current or most recent occupation	Professional or higher administrative	14
	Sales or service	2
	Skilled & clerical	1
	Household duties	2
	Other (including student)	5
Current employment status	Employed full time	6
	Occasionally employed	1
	Retired	12
	Student	5
Financial situation (subjective assessment)	Well above average	5
	Slightly above average	8
	Average	5
	Slightly below average	4
	Well below average	2

Total $N = 25$, however 1 participant chose not to disclose any demographic information

It had been intended to collect equal sized samples of participants in each of the conditions. However, opportunistic community sampling had resulted in an imbalance in numbers: condition 1 (structured: QoL questionnaire) $N = 12$; condition 2 (semi-structured: descriptive prose with headings) $N = 7$; and condition 3 (unstructured: descriptive prose without headings) $N = 6$. Because both condition 2 and 3 were descriptive prose tasks, the data from these were combined. Consequently the study sample was split into two groups: 1) those completing the structured questionnaire – Questionnaire Group, and 2) those completing semi or unstructured descriptions of their QoL – Descriptive Prose Group.

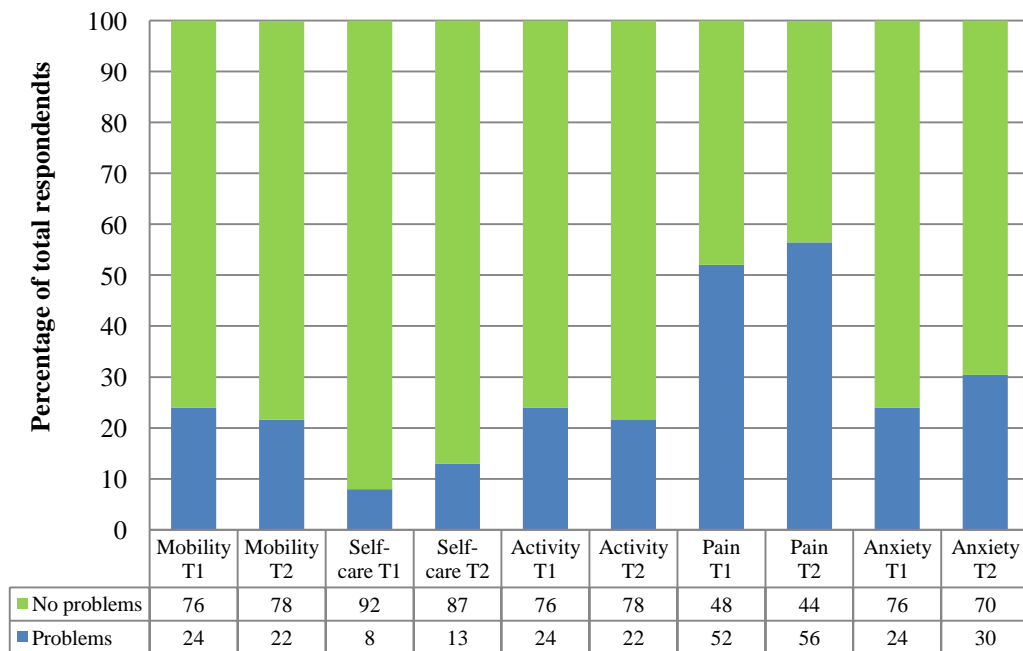
4.3.1 Statistical analyses - T1 & T2

4.3.1.1 T1 and T2 scores

T1 data were collected from all 25 participants, and T2 data from 23 participants. Table 4.2 shows mean scores for EQ-5D VAS, the PANAS and the GOSS-Q by experimental condition (Questionnaire Group or Descriptive Prose Group).

As shown in Figure 4.7, the percentage of participants reporting problems at T1, as measured by the EQ-5D health profile, were: mobility 24%; self-care 8%; usual activities 24%; pain/discomfort 52% and anxiety/depression 24%. Respective percentages of participants reporting problems at T2 were: mobility 22%; self-care 13%; usual activities 22%; pain/discomfort 56% and anxiety/depression 30%.

Figure 4.7 Frequencies of respondents reporting problems or no problems for each EQ-5D facet at T1 and T2



T1, $N = 25$; T2, $N = 23$

4.3.1.2 Main effects over time

Table 4.2 Mixed factorial MANOVA analysis with time as the within-subjects factor, and condition as the between-subjects factor

Variable:		<i>N</i>	T1 mean	T1 <i>SD</i>	T2 mean	T2 <i>SD</i>
EQ-5D VAS	Questionnaire	10	85.60	11.75	85.80	11.21
	Descriptive prose	9	84.78	10.79	84.11	10.85
PANAS Positive Affect	Questionnaire	10	30.00	8.18	30.00	10.34
	Descriptive prose	9	34.00	7.73	33.11	8.62
PANAS Negative Affect	Questionnaire	10	12.82	3.37	12.50	3.48
	Descriptive prose	9	10.77	1.74	11.00	1.90
GOSS-Q	Questionnaire	10	27.00	5.72	27.33	6.26
	Descriptive prose	9	26.69	5.78	26.91	5.07
MANOVA <i>df</i> = 4,14		<i>F</i>	<i>p</i>	η^2		
Within subjects main effect of time		.776	.559	.181		
Between subjects' effect of condition (Questionnaire / Descriptive prose)		1.74	.197	.332		
Interaction:						
Time * condition		0.54	.707	.134		

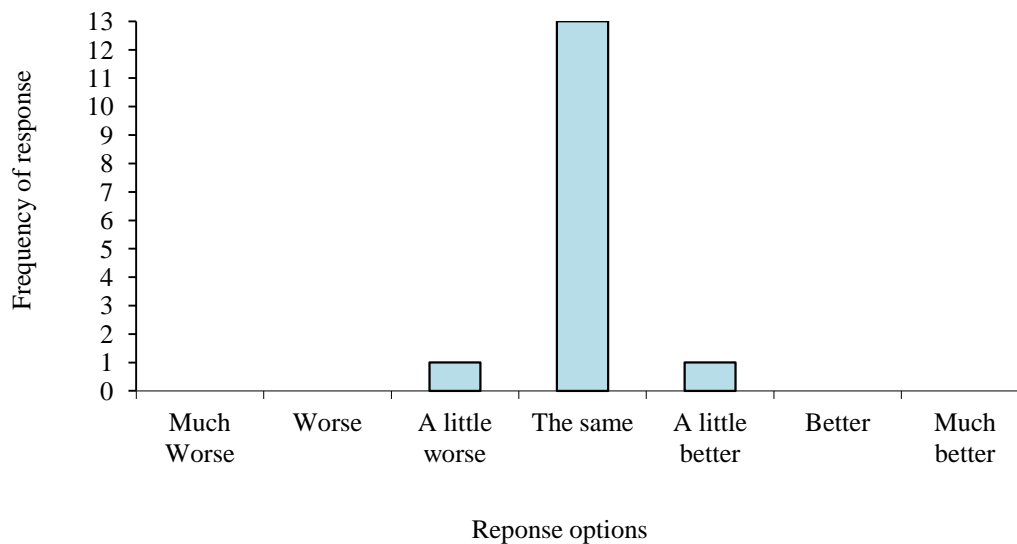
As shown in Table 4.2, a mixed factorial MANOVA revealed that there was no significant main effect of time ($F(4,14) = .78, p = .56$) Neither was there any main effect of condition ($F(4,14) = 1.74, p = .20$) and no significant interaction was found between time and condition ($F(4,14) = 0.54, p = .71$). Univariate tests from the analysis also confirmed no significant effect over time for any of the measures and between subjects contrast confirmed no significant differences between conditions for any measure ($p > .05$ in all cases). The hypothesis that thinking about one's QoL would have an effect on immediate post-task measures of QoL self-ratings, mood and QoL-related goal orientation was therefore not supported in this analysis. These results also suggested that the second hypothesis that thinking about one's own QoL in a structured format would have a stronger effect than a semi-or unstructured approach, was similarly not supported.

4.3.2 Post study evaluation of change (T3)

4.3.2.1 Ratings of change

The post-study evaluation of change questionnaire was completed by 15 participants from the full sample of 25. Eight of these had been in the QoL questionnaire group and 7 in the descriptive prose group. As can be seen in Figure 4.8 the majority of these respondents ($N = 13$, 87%) stated that their QoL had not changed as a result of taking part in the study. Of the remaining two respondents, one felt QoL had become a little worse, and the other, a little better.

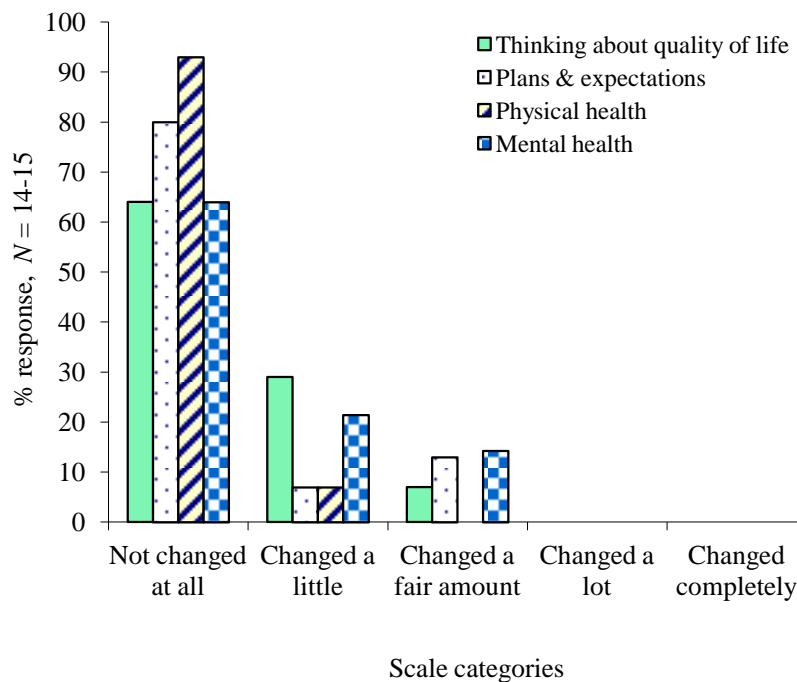
Figure 4.8 Ratings of QoL change as a result of taking part in the study



Results from questions asking about changes in the way they *thought* about their QoL, and/or changes in their plans and expectations, physical or mental health revealed that 6 respondents (40%) reported that they perceived some degree of change on one or more of these dimensions. In response to the question “*How much has participating in this study changed the way you think about your quality of life?*”, nine of the 14 respondents who answered this question (64%) stated that it had not changed at all, whilst four (29%) felt it had changed a little. Only one respondent perceived that the way they thought about their QoL had changed by any more than this. Twelve respondents (80%) stated that their plans or expectations for the future had remained unchanged. Regarding their physical health, 93% ($N = 14$) of respondents stated that this had remained unchanged. For mental health however, whilst nine of the 14 respondents who answered this

question (64%) reported no change, 3 (21%) suggested it had changed a little, and another 2 (14%) indicated they felt it had changed by a fair amount. These results are illustrated in Figure 4.9 and indicated that, of all the possible changes investigated, mental health was most frequently reported as having been perceived to change as a result of taking part in the study.

Figure 4.9 Ratings of change resulting from the study



Participants reporting changes at T3 versus participants reporting no changes at T3 (total $N = 15$)

As mentioned earlier, 15 participants completed the T3 questionnaire. The scores of the 6 participants who reported changes were also examined in relation to the other 9 who had reported no change on any variable. In this comparison there was a gender difference in the two groups (of those reporting changes 16% were male, of those reporting no change 33% were male). The mean age of those reporting changes was 43 years, but was 61 years for those reporting no change, although this difference was not significant ($t(12) = 1.562, p = .144$).

Further exploratory examination of the data showed that participants who reported change at T3 had significantly lower positive affect at both T1 and T2 than those who had reported no change (T1: $t(12) = 4.81$, $p = .001$, T2: $t(11) = 5.26$, $p = .001$). A significant difference between the groups was also found for negative affect at T2 ($t(11) = 3.75$, $p = .003$) showing those who reported change at T3 to have higher negative affect when they completed the PANAS at T2 (see Table 4.3). MANOVA analysis of the PANAS score revealed a significant interaction between time and positive affect ($F(1,10) = 9.308$, $p < .05$) showing that while the positive affect scores of those who reported change decreased between T1 and T2, the scores of those reporting no change increased between these time points. This result indicated that the direction of movement of positive affect was related to perceived change. No significant differences were found between the change and no change groups for the EQ-5D VAS or the GOSS-Q.

Table 4.3 Exploratory analysis of differences in outcome measures at T1 and at T2 with “reporting change at T3” and “reporting no change at T3” as the between-groups factor

Outcome measure		EQ-5D VAS		Positive Affect		Negative Affect		GOSS-Q	
		T1	T2	T1	T2	T1	T2	T1	T2
Change Group	Mean	78.80	79.20	22.67	19.67	14.50	15.00	24.00	23.83
	SD	11.90	11.00	5.09	5.92	3.83	3.58	5.51	5.98
	N	5	5	6	6	6	6	6	6
No Change Group	Mean	87.00	90.17	35.50	37.71	10.63	10.43	25.89	25.71
	SD	8.79	6.68	4.84	6.37	0.74	0.54	5.99	4.82
	N	9	6	8	7	8	7	9	7
Between groups	t	1.480	2.045	4.806	5.258	2.335 ^a	3.748	0.617	0.629
	p^1	.165	.071	.001 ^{***}	.001 ^{***}	.061 ^a	.003 ^{**}	.548	.542
	df	12	9	12	11	5.68 ^a	11	13	21

¹ $p = 2$ -tailed

^a equal variances not assumed (Levene's test $< .05$)

* significant at $p = .05$

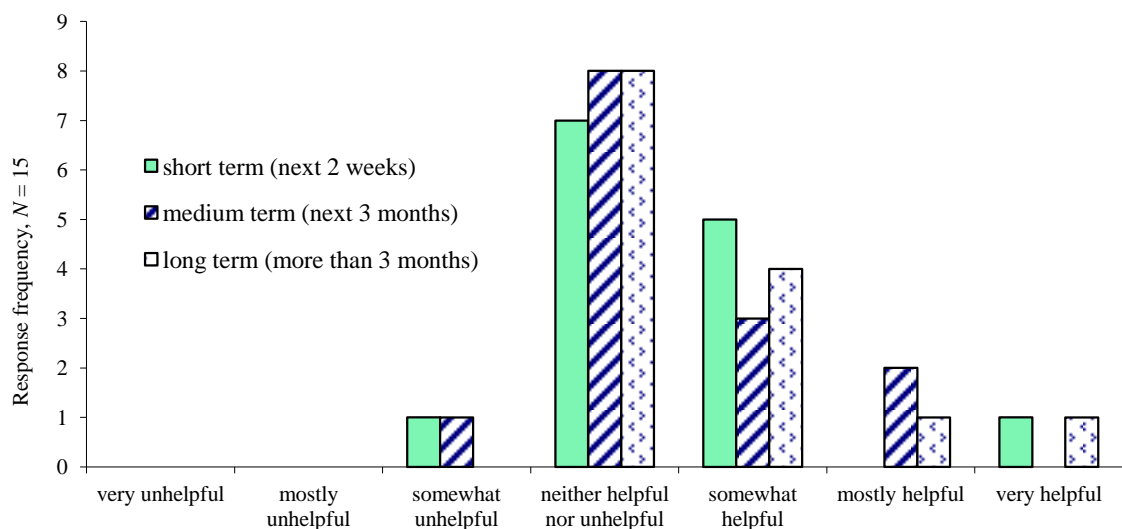
** significant at $p = .01$

*** significant at $p = .001$

4.3.2.2 Ratings of helpfulness

T3 participants also indicated whether they anticipated their experience of the study would be helpful to them over the short, medium and long term. Half of the respondents ($N = 7$) reported that they felt it would be helpful in the future at one or more of the time points. Only one participant stated that their experience of taking part in the study would be unhelpful. The remaining six stated the experience would be neither helpful nor unhelpful at any of the time points. Figure 4.10 shows the more detailed results and illustrates how similar patterns of anticipated helpfulness were found for each of the time points (short term $N = 6$; medium term $N = 5$; and long term $N = 6$).

Figure 4.10 Reported patterns of future anticipated helpfulness of the study



4.3.2.3 Qualitative results

Qualitative data elicited from comments provided insights into some of the quantitative responses. A selection of illustrative excerpts is given below however full transcripts of participants' responses can be found in Appendix P.

Helpfulness of taking part in the study

A number of the comments suggested that participants had found positive value in taking part:

"It has made me realise how fortunate I am to have a positive view of my life"
(female, age 77)

“The process of writing/scoring scales on how I feel has helped me reflect and realise that actually I’m happier than I thought.” (female, age 25)

“...I feel better and do believe that was because of the study....thanks for helping me reflect!” (female, age 25)

“The more you evaluate your QoL the more you realise what elements of your life make a difference to you, and the more you can focus on them.” (male, age 28)

Self-perceived changes as a result of taking part

Some participants also identified specific areas of their lives where they perceived that their thoughts, expectations or behaviour had changed as a consequence of taking part in the study. These comments also reflected their innate standards or expectations of QoL:

“[Taking part in the study has] reinforced the need to remain involved and active in creative pursuits” (female, age 63)

“I’m trying to focus on the positive side of my life so I can feel content.” (female, age 34)

“Just thinking about the question which asks about where you are in relation to your ideal helps shape my goals and helps me recognise what my goals and ideals are and what I have already achieved.” (female, age 25)

“[Taking part in the study has]encouraged me to do more exercise.” (female, age 28)

Participants also reflected on the methodology employed in the study and how this had impacted the ways in which they thought about their QoL:

“The more you evaluate your quality of life the more you realise what elements of your life make a difference to you, and the more you can focus on them.” (male, age 28)

“The study has made me reflect a little more about my life and all the things that I am able and willing to do. It’s good to have a wakeup call every now and then.” (female, age 25)

“I found the questionnaire very interesting to complete. I made me think that I can be quite hard on myself and on what I have achieved.” (male, age 25)

Negative outcomes

The comments of two participants suggested that taking part in the study had not been a universally positive experience. For one this was related to a realisation of the responsibility she held for her own wellbeing. For the other, their experience was contextualised in terms of other responsibilities and life events.

“[The study has] made me aware of how much my vulnerability and wellbeing is in my own hands and quite fragile.” (female, age 63)

“I’m too busy and involved with other things, so your questionnaire has not really made an impact on me.” (female, age 68)

However, in response to the question *“How much has your quality of life changed as a result of taking part in this study?”*, only one participant suggested that it had become any worse, providing the explanation:

“Because I can drive I can attend my social activities and realise how much I rely on having a car.” (female, age 78)

4.4 Discussion

4.4.1 Main findings

The aim of this study was to investigate whether the cognitive process of thinking about QoL could, in itself, have a subsequent effect on self-ratings of QoL, mood and QoL-related goal orientation. It had been predicted that there would be an effect on immediate post-task measures. Furthermore it had been expected that thinking about one’s own QoL in a structured format would have a stronger effect on post-task measures than formats using a semi or unstructured approach. The results of the statistical analysis of study data suggested that that neither of these hypotheses was supported, as no significant differences were found in any of the measures after the thinking task had

been applied. This was also true for both structured and semi, or unstructured, cognitive approaches.

The conclusion drawn was that the process of thinking about QoL did not, in itself, affect subsequent self-ratings of QoL, mood and QoL-related goal orientation. This finding concurs with earlier studies which similarly concluded that QoL instrument completion had no positive effect on emotional wellbeing in cancer patients (Velikova et al., 2004) or on self-reported QoL for lung transplant patient (Santana et al., 2010). However, there exist substantial methodological differences between these and the current study. Both the studies cited included only patient participants and instruments were completed in clinical settings, with the primary focus being on patient-physician communication. Furthermore, alongside clinical management indicators, only standard QoL intervention measures were used in the previous studies, unlike the present study which also included a descriptive prose method of facilitating thinking about QoL, as well as completion of the WHOQOL-BREF instruments. By using a variety of methods, a heterogeneous community sample and completion of the instruments and tasks outside healthcare settings, it was intended that the present study would provide a more naturalistic perspective on whether reflecting on QoL would bring about effects on wellbeing. The present study also included consideration of effects on mood and goal-oriented QoL.

Interestingly, a previous postal questionnaire study also found no effects of instrument completion, suggesting that this might have been due to the absence of an interviewer, or to respondents having more flexibility regarding when and where to complete the questionnaire (French et al., 2009). The implication is that where reactivity effects are found, these may inadvertently be due to, or exaggerated by, both experimenter and methodological influences. Consideration should therefore be given to these potentially confounding variables in the design of future studies.

4.4.2 Evaluation of change

Whilst results from the statistical analyses did not provide evidence to support the stated hypotheses, data from the post-study evaluation questionnaire, however, was somewhat less conclusive. While the data from some participants concurred with the supposition

that thinking about QoL had no subsequent effects, others pointed to different perceptions. For example, 36% of those who completed the post-study evaluation of change questionnaire reported that participating in the study *had* changed the way they *thought* about their QoL. Whilst four fifths of respondents felt nothing had changed regarding their plans or expectations for the future and almost all (93%) felt it had made no difference to physical health, more than one third of respondents (36%) reported that they felt their mental health had changed in some way. Such responses seem at odds with the findings from the statistical analysis and suggested that some self-perceived change had occurred, at least for a proportion of participants.

It seems, therefore, that the analysis of the outcome measures and the post study evaluation of change elicited discrepant results. By way of possible explanation, it may be that the outcome measures employed lacked sensitivity in that they could not detect the subjectively self-reported identified changes. Although the EQ-5D is generally considered to be a valid and reliable measure, its responsiveness has been called into question with ceiling effects found relating to the descriptive system (Goodwin, Ratcliffe, Morris, & Morrissey, 2011; Haywood, Garratt, Lall, Smith, & Lamb, 2008). The GOSS-Q scale was developed for this study and furthermore the original version (GOSS) has only been cited in two other published to date (Dibb & Yardley, 2006; Yardley & Dibb, 2007). As such its sensitivity to change had not been established by the developers prior to its application in this research. Alternatively it may be that any changes were too small to be detected statistically, a factor which may also be related to the relatively small sample size of this pilot study.

Another possibility is that participants completed the T1 and T2 measures in a cognitively different way from the post study evaluation of change questionnaire. They may have approached what they saw to be overtly psychometric measures differently from the qualitative evaluation of the study processes at T3. It has previously been found in cognitive interviews that answers to response scales can be inconsistent with verbalised reasoning (French et al., 2007) and thus it is possible that a similar inconsistency might have been evidenced here. Additionally, the post-study evaluation of change questionnaire was administered when participants had been given time to reflect back upon the study, whereas T2 data was collected immediately after completion

of the QoL thinking task. It must also be remembered that only a subsection of the larger sample completed the evaluation of change questionnaire and it is unknown whether those who did not complete it perceived changes to have occurred. Thus to generalise the results necessitates caution.

A notable finding of the study was that it appeared that those participants who reported changes differed from those who reported no change: they had lower positive affect and higher negative at both time points in the study and higher negative affect at T2. Moreover their positive affect scores reduced after completing the QoL task. Whilst the deleterious effects of mood on QoL is well established (Guajardo et al., 2011) , it seems that reflecting of QoL might conversely have exacerbated lower mood for a small number of the sample. However, whilst these individuals with lower mood reported change more readily, what was not discernible from the study data was the direction of that change. It was therefore not possible to tell from the questions used and responses given whether they saw the perceived changes as positive or negative. Nevertheless, the possibility that any change could have been perceived as negative is an indicator that caution should be applied in future studies in relation to participants with low mood.

In summary, while the main analysis clearly suggested that thinking about QoL did not, in itself, affect subsequent self ratings of QoL, mood and QoL-related goal orientation, the contradictory nature of some of the post-study evaluation data makes it difficult to state this conclusively. Interestingly, half the evaluation of change respondents reported they would find taking part to be helpful in the future. Themes emerging from the qualitative data further suggested that reflecting on QoL could be an interesting exercise and a positive experience. Furthermore, the data suggested that thinking about QoL could have value in terms of helping individuals to appreciate their current situation and to evaluate this in relation to their goals and standards. This finding lends support to the WHOQOL definition of QoL where self-judgements are contextualised within one's goals, standards and expectations. Whilst many of these emerging themes were encouraging, it is necessary to draw conclusions from the data with caution. Even though the survey was administered by post and the researcher was therefore remote from the participants during administration, this reduces, but does not negate potential experimenter effects.

4.4.3 Findings relating to self-regulation theory

The findings of this study should also be considered within the context Carver & Scheier's (1998) theory of self-regulation (SRT) as discussed in section 4.1. Reviewing the results within this framework, a number of possible conjectures emerge. Firstly, it is possible that, for at least some of the sample, the reflecting tasks participants were asked to complete were insufficient to bring about a greater awareness of their present condition, thus meaning the input function stage of the feedback loop was not fully activated. However, a small number of those taking part in the post-study evaluation made clear reference to the value of reflecting on their lives, suggesting that this stage had indeed been reached for those individuals. Secondly, as participants were asked to think about their current QoL rather than to think about what QoL they would aspire to, the reference value element of the feedback loop (providing information about what is desired or intended, i.e. a goal) was outside the remit of the study. Indeed, the concept of goals was only mentioned once in the qualitative data from the post-study evaluation, suggesting that it was not salient in this context. Even if participants had achieved completion of the earlier input function stage, in that they recognised and appreciated their current condition, they may not have spontaneously then gone on to consider their goals or expectations for the future. Thirdly, given that the participants were not specifically asked to think about their goals and were unlikely to have therefore identified them, it was even more uncertain that the study would provide any evidence of the presence of the comparator stage of the feedback loop. Finally, as the tasks in this study were thus effectively confined to the input function stage, it is unsurprising that no evidence was found of the output function stage i.e. behaviours with the goal of reducing any discrepancy between the input and the comparator. Neither would evidence be expected of the impact on environment stage i.e. creation of change in the present condition, leading to a different input perception. That the focus of the tasks was on the early stages of the feedback loop makes the absence of measured changes in post-task self-ratings unsurprising. As such the SRT model provides a plausible explanation for the findings of this study.

4.4.4 *Study limitations and future directions*

Reflecting on the results of the study, a number of methodological limitations were noted. Firstly, in the post study evaluation of change questionnaire, whilst participants were asked to identify whether changes had occurred for them, with the exception of overall effects on QoL, they were not asked to identify the direction of changes perceived i.e. whether these were positive or negative. Secondly, participants were only asked to think about whether they thought they would find their experience of taking part in the study to be helpful in the future. In hindsight, it might also have been useful to understand *why* they might, or might not, find it useful as this might identify individual differences and allow insights into potential improvements in methodology.

Thirdly, as discussed earlier, there may have been methodological influences on measurement reactivity in operation. French and Sutton (2011) suggested that reactivity may be exacerbated by repeated administration of measures and that it can therefore be reduced by requiring participants to complete a measure on a single occasion only. Although this is a valid argument, this design could be problematic for intervention studies as it would remove the baseline measurement against which to assess change. An expedient approach, with a larger sample, would be to adopt a randomised study design with three independent arms: 1) pre-test measures only; 2) post-test measures only; and 3) both pre and post-test measures. This would then allow comparison of the scores of these groups. However, whilst for two of the groups in this design, single administration might legitimately reduce measurement bias, it would be difficult to estimate by how much, and neither would this remove the possibility of reactivity arising from the single administration itself.

Another method of trying to disentangle the effects of different tasks and measures in behavioural studies is to adopt a 2 x 2 Solomon design. In this design the sample is divided into four groups. Two of the groups complete the tasks and two do not. Further, two of the groups complete the pre-test measures and two do not. The result is that within each task condition there is one group that is measured and one that is not. By explicitly including measurement as a factor in the design, it is thus possible to investigate the independent and combined effects of tasks and measurement. For example, a recent study into the effect of wearing a pedometer took a similar approach. Here participants were randomised to receive a pedometer or no pedometer, and to

receive a pre-test walking behaviour and health beliefs questionnaire or a health beliefs questionnaire that made no reference to walking or physical activity. Findings indicated that those wearing pedometers walked more, but so too did those who completed the pre-test walking behaviour questionnaire (Spence et al., 2009). Albeit attractive, this type of design can prove impractical in small studies as it requires large overall numbers of participants in order to satisfactorily populate each group. Although this type of approach may be practical in many laboratory based studies, it may be less pragmatic in field based research with community sampling.

It must also be acknowledged that, as a pilot investigation, the sample size was small in the present study and opportunistic convenience sampling may have resulted in a self-selection bias. The majority of the sample were female and predominantly well educated, which has implications for the generalisability of the findings to a wider population. A further limitation was participant attrition. As mentioned earlier, although all participants who responded to the invitation to participate completed both the pre and post tests, only 15 of the 25 also returned the post-study evaluation of change questionnaire. It may be that sending this questionnaire as a separate mailing affected response rates or that this additional element was too burdensome.

4.4.5 Conclusion

It was intended that this study would give insight into the wider effects of thinking about QoL. The present study differed methodologically from earlier studies in terms of intervention components and community sampling, but findings concurred with earlier studies that had suggested that the process of thinking about QoL has no significant effect on subsequent self-ratings of QoL or emotional wellbeing. In addition, no main effects on mood and QoL-related goal orientation were found and neither of these outcomes had been previously tested.

Although apparently inconsistent findings amongst some of the post-study evaluation data, plus acknowledged sample restrictions, mean these conclusions should be viewed with a degree of caution, the present pilot study nevertheless tentatively established the principle that simply thinking about one's QoL, with or without the assistance of a structured questionnaire, is insufficient to bring about changes in subsequent subjective

judgements. The next research study (Chapter 5) was therefore able to be developed. This next study explores the effects for individuals of providing structured and guided feedback on self-assessments of QoL, and tests the impact of that guidance.

CHAPTER 5. STUDY 3: INVESTIGATING THE EFFECTS OF PROVIDING FEEDBACK ON SUBJECTIVE JUDGEMENTS OF QUALITY OF LIFE

5.1 Introduction

The conclusions of Study 2 suggested that the cognitive process of thinking about one's own QoL did not, in itself, bring about changes in subsequent subjective judgements of QoL. Having established this principle, the next stage of the research was to investigate the effects, for individuals, of providing structured and guided feedback on their self-assessments of QoL, within the context of SRT as described in Chapter 1.

A number of studies have examined the effects of providing feedback on QoL on a multiplicity of outcomes. One area of research has been into the effects on patient-physician communication. For example, a Dutch study by Detmar et al (2002) found discussion of QoL related issues was significantly more frequent where a graphical summary of the QoL assessment was provided to patients and physicians prior to each consultation. Moreover 87% of patients in the study reported their subjective view that provision of QoL information in this way had facilitated communication. Others have similarly found that using QoL information increases the incidence of dialogue about symptoms and other QoL related topics (Detmar & Aaronson, 1998; Hilarius et al., 2008; Santana et al., 2010; Takeuchi et al., 2011; Velikova et al., 2004).

The effects of QoL feedback on processes of care & patient management has also been an area of interest. For example, it has been asserted that QoL information can be used to facilitate healthcare professionals' understanding of matters that impact the patients' health in ways that might be overlooked in the traditional medical model (Detmar et al., 2002). In this regard, health care professionals' awareness of patients' health issues has been found to benefit from the application of QoL feedback. Physicians have been found to identify a greater proportion of patients with moderate to severe health problems when QoL questionnaires are used, as opposed to normal care without QoL questionnaire completion (Detmar et al., 2002). Relatedly, nurses' awareness of patients'

levels of daily activity, pain and overall QoL has also been found to be better when QoL profiles are utilised (Hilarius et al., 2008). In a structured review, Marshall et al (2006) also concluded that the diagnosis of mental health conditions was particularly affected when PROMs results were fed back to clinicians, finding improvement in health professionals' ability to detect conditions.

As illustrated above, although literature undoubtedly exists regarding the utility of QoL information, clearly much of the focus on outcomes has been on the potential application within healthcare processes and to the benefit of physicians or nursing staff in terms of process outcomes. A useful systematic review of the impact of PROMs in clinical practice was provided by Valderas et al. (2008, p. 191). This review presented evidence from 28 randomised controlled trials where interventions consisting of PROMs administration with feedback to clinicians were compared with routine clinical practice (without PROMs). It reported that while most studies found intervention effects on a least one aspect of the process outcomes they assessed, effects on patient health status were not frequently observed, nor formally assessed, leading the authors to conclude that *“considerable work is still required before clinicians can invest resources in the process and rely on consistent evidence for the benefits for their patients”*. This conclusion highlights the need for person-centred research into those individual patient benefits that might be generated by QoL assessment. For example, these benefits may stem in future from clinicians' use of QoL information to allow improved targeting of treatments or from greater shared decision making based on a better understanding of individual patient's expectations.

Although, as suggested, relatively little research has looked at patient centred outcomes of QoL feedback, some work has begun into examining the effects of QoL assessment on individual patient satisfaction. However, these studies have generally yet to find positive effects resulting from the utilisation of QoL information (Gutteling et al., 2008; Hilarius et al., 2008; Mills, Murray, Johnston, Cardwell, & Donnelly, 2009; Rosenbloom, Victorson, Hahn, Peterman, & Cella, 2007). One exception is study by De Wit et al. (2008) who found that adolescent diabetes patients who completed QoL assessments, and discussed the outcomes with their paediatrician, were more satisfied with their care than those receiving usual care.

Only a handful of studies have specifically considered improvements in patients' QoL as an outcome of feeding back data to healthcare professionals and to patients. Moreover, some of these have also only done so as a secondary effect of improving other processes within the healthcare interactions. For example the seminal study by Velikova et al. (2004), as previously described in Chapter 4, section 4.1, was primarily concerned with the effects of QoL measurement on patient-physician communication with effects on patient well-being subsequently assessed only as a secondary outcome. Nevertheless, while Velikova and her colleagues found positive effects from QoL assessment, both for scores on the FACT-G and its physical health subscale, they also found that positive effects on the emotional well-being subscale only occurred for those whose QoL assessment results had additionally been fed back to their clinician. This suggested that although the QoL assessment had itself led to some measureable differences in scores, the feedback component of the intervention had been the active ingredient in bringing about improvement in emotional well-being.

Other studies which have more directly researched individual QoL as an outcome have provided contradictory evidence regarding the effects of feedback. Some have found no effects on well-being (Hilarius et al., 2008; Rosenbloom et al., 2007; Santana et al., 2010) while others have found positive effects on psychosocial health, behaviour, mental health and family activities (De Wit et al., 2008) and on disease specific and mental QoL (Gutteling et al., 2008). These studies are discussed in more detail below.

Hilarius et al. (2008) conducted a study into the efficacy of QoL assessment in routine outpatient chemotherapy treatment, using repeated measures in a sequential cohort design. Two months after the first cohort had formed the usual care control arm, the second, experimental, cohort completed the standardized EORTC QLQ-30 QoL questionnaire, and a condition specific module, at each of 4 outpatient clinic appointments, using touch screen software with results summarised graphically. Results were given to patients and nurses immediately prior to the subsequent consultation with written information on how to interpret the summary scores. No specific guidelines were provided as to how the data should be used. Although positive effects were found in terms of improvement in patient-physician communication and nurses' awareness of patients' QoL, no significant differences were found between the QoL of the intervention and control groups at the fourth clinic visit. However, this study was

limited as, although guidance was provided to interpret the scores, no protocol was offered for using the data. Furthermore, the instructions given for use in the consultations stated that it was not obligatory to address all the topics provided in the QoL information summary. It is therefore plausible that this ambiguity over how the data could, or should, be used during the consultations may have led to its inconsistent application in the study. Recognising that patients' own management of their health may have affected health outcomes, the authors also proposed that additional elements, such as tailored health education based on individual responses and telephone coaching could have potential in enabling better self-management of health concerns in future interventions.

Another oncology study by Rosenbloom et al. (2007) examined whether offering interpretive assistance of HRQoL (FACT-G) results to treating nurses affected patient outcomes (QoL, patient satisfaction and clinical treatment). For each item in the FACT scale, participants were asked to answer the question and then to rate whether their experience of that problem was better than, worse than or as expected. In a 3-armed study, the control condition cohort completed the Functional Living Index-Cancer (FLIC) at baseline and 3 months and also the FACT-G at 6 month follow up. In the assessment control condition participants completed both assessments at baseline, 1, 2, 3 and 6 months, with the FACT-G results also presented to treating nurses prior to patient visits. In the structured interview condition, patients completed the questionnaires at each time point and were interviewed afterwards by a research nurse at the 1 and 2 month visits. Patients in this latter group were shown their FACT record form and interviewed about any extremely negative responses or where they felt their responses were worse than they had expected. The interviewer was tasked with recording extremes of functional status, where there were disparities with patient's expectations and any elaborations of those disparities, and then relaying this more detailed feedback to the treating nurse. Results found no improvement in the QoL or satisfaction of participants in any group or any differences between the groups in terms of clinical treatment changes. The authors postulated that the intervention may not have been sufficient to improve HRQoL and that, rather than mere notification of nursing staff to a problem, additional treatment recommendations might have had a greater effect. It is also possible that feedback to physicians rather than nurses might have had different effects, particularly if the former were more influential on clinical management decisions. One limitation of

the study, acknowledged by the authors may also be the possible lack of sensitivity of the outcome measure. Furthermore, Rosenbloom and her colleagues accepted that information elicited in the interviews was dependent on patients' spontaneous elaborations and may not have been sufficiently detailed to increase the meaningfulness of their QoL scores to treatment nurses. It is also plausible that deliberately focusing on poor and "lower than expected" QoL during the interviews may have acted to suppress positive effects that may otherwise have been generated from a more balanced review of holistic QoL.

A more recent study by Santana et al. (2010) examined the use of QoL measures in the routine care of lung-transplant patients at each clinic visit over a six month period. In this study patients completed the Health Utilities Index (HUI) Mark 2 and Mark 3 on touch screen computers either with (intervention group) or without (control group) feedback to clinicians. Training was provided to the clinician in how to interpret the feedback, which took the form of a graphical "score card". All patients completed the EQ-5D at the end of every visit to provide the QoL outcome measures (the other primary outcome measures being a communication score and a patient management score). At the end of the study no differences were found between intervention and control groups in terms of QoL, although small improvements in communication and patient management were detected. It was concluded that the lack of effect might be, at least in part, due to a lack of responsiveness of the EQ-5D measure, and the choice of this as a generic, preference based measure rather than one which is disease-specific. The authors also recognised that the design of the study may have been problematic as clinicians' experience in using the HUI with the intervention group may have contaminated their practices with patients in the control group. Furthermore, patients were seen by different clinicians at different visits and whilst in some consultations patients met with an individual clinician, in other consultations patients met with two clinicians. These variables may have diluted any effects due to lack of consistency of method and application of QoL scores.

Other studies, however, have provided more optimistic results for the application of QoL feedback. For example the study mentioned earlier by De Wit et al. (2008) found that monitoring and discussing QoL with adolescents with type 1 diabetes had positive impacts on their well-being as well as on their satisfaction with care. In this study

patients in four outpatient clinics were randomly assigned to either a control or intervention arm. Adolescents in the control group received their usual care but, to control for questionnaire completion before their consultation, completed a lifestyle rather than a QoL questionnaire. Adolescents in the intervention group instead completed the Paediatric Quality of Life Inventory (PedsQL) Generic and Diabetes-specific modules, the results of which were discussed with them during their appointment. All questionnaire administration was on a computer for both groups. Outcome measures were physical and psychosocial well-being (measured using the Child Health Questionnaire – CHQ); depression (Centre for Epidemiological Studies Scale for Depression – CES-D); diabetes-specific family conflict (Diabetes-Specific Family Conflict Scale – DFCS); satisfaction with care (Patients’ Evaluation of the Quality of Diabetes Care – PEQ-D) and glycaemic control (A1C values). For the intervention group, mean scores in CHQ subscales of psychosocial health, behaviour, mental health and family activities improved, except for those adolescents with the highest A1C values. It was also found that, regardless of A1C values, adolescents in the intervention group were more satisfied with their care and reported higher self-esteem at follow-up than those in the control group. Considering these results, the authors pointed out that improvements were found in the intervention group despite relatively high levels of well-being at study entry. However they accepted that similar results may not be found for teenagers with poorer psychological profiles. This study was also subject to large refusal rates at study recruitment, which may have contributed to selection bias in the sample. To try to ensure consistency of feedback, clinicians in the study were given specific instructions as to what QoL scores to discuss and in what order. Indeed, they were given a checklist to complete to document topics and discussions. However, it remains a limitation of the study, acknowledged by the authors, that no method was included for assessing how the feedback was given in practice, nor for observing the interaction.

A Dutch study by Gutteling et al. (2008) investigated the effectiveness of computerized measurement and feedback of QoL to the physicians of chronic liver disease patients. Patients regularly completed computerised QoL questionnaires before each consultation for the period of one year. These questionnaires measured disease-specific QoL (the LDSI 2.0), generic QoL (the SF-12), and patient satisfaction (the QUOTE-Liver). The physicians of patients in the intervention group were able to obtain immediate,

computerised, graphical outputs of current and previous QoL scores, whereas physicians of those in the control group carried out their usual consultations. Although the main analysis of the study found no improvement in QoL for the patient group as a whole, secondary analysis revealed positive results in terms of disease-specific QoL for older patients and mental QoL for older and male patients. Although one strength of the study was the inclusion of additional analysis beyond main effects, no explanation was offered for the positive results found for the particular sub-groups.

The results from these previous studies provide a mix of evidence on the effects of feeding back QoL information. While some have found no effects on wellbeing, others have found limited effects relating to specific subscales or to specific sub-groups within the study sample. The evidence nevertheless suggests that people would like to talk about their QoL. Examining patient preferences for feedback, Detmar et al. (2000) found that not only did more than 95% of the palliative chemotherapy patients in their study express a desire to discuss the physical aspects of their illness, more than 90% also stated that they wanted to discuss their feelings and problems in their daily lives. Despite this, few researchers have investigated relative efficacy of different methods of feedback. However Brundage and his colleagues have reported a series of studies into presentation formats for longitudinal QoL information (Brundage, 2002; Brundage et al., 2005; 2003). Findings from oncology patients suggested simple formats were most preferred, with line graphs rated highest for ease of understanding and helpfulness.

5.1.1 Original research

There exists, therefore, a small literature base to which this programme of research contributes. However, the research here differed from previous studies in a number of ways. Firstly, unlike the present research, no studies are evident in the existing literature whose methodologies include feedback of *both* QoL *and* the importance individuals attach to its various aspects. Although some studies have attempted to consider importance in terms of “bothersome issues” or “important concerns” as defined by low QoL scores (Snyder et al., 2011) or high totals on concerns checklists (Baile, Palmer, Bruera, & Parker, 2011; Lidstone et al., 2003) they have not included feedback. In other studies the importance of QoL has been measured but in cross-sectional study designs at population or population sub-group levels (da Rocha, 2011; Molzahn et al., 2011;

Molzahn et al., 2010; Skevington & O'Connell, 2004; C. Wu, 2009). In one study the differences between QoL ratings and importance ratings were considered, but this was in relation to particular populations and the results were not individualised (Skevington & O'Connell, 2004). This thesis utilises an original methodological approach, not only considering QoL and importance scores in combination, but at a person-centred level, and over time. Whereas previous studies into the effects of QoL feedback have not considered importance, by being able to compare QoL and importance scores, participants in the present study can recognise those aspects of QoL that might be a priority i.e. those aspects they consider to be highly important but where current QoL is relatively less good.

Secondly, as reported earlier in section 5.1, many prior studies have primarily sought to understand the impact of QoL feedback on patient-physician communication or process of care. As suggested, later studies have investigated the QoL of participants themselves as an outcome, but this has often not been their sole focus. The study described in the present chapter, took a fundamentally person-centred focus and one which was outside the healthcare system. Rather than being concerned with the usefulness of feedback from a clinical practice perspective, the research sought to focus on the utility of the feedback approach purely in terms of improvements in individuals' wellbeing. The rationale for this was to begin to develop a practical methodology for promoting effective self-management for individuals, via an individualised feedback intervention. The intention was that this could be thereafter equally applied to patients within healthcare systems or to persons in the community who might wish to have the opportunity to consider their QoL and to identify those areas to which to direct their efforts in order to support, and improve, their wellbeing. The inclusion of feedback of both QoL and importance scores was also designed to fulfil both the input function and reference value stages of the feedback loop of Carver and Scheier's (1982, 1998) Self-Regulatory Theory (SRT), as discussed in Chapter 2, section 2.3. By taking this approach, it was intended that the feedback would enable individuals to identify the differences between their perceptions of their current states and their external values or desired states.

Aligned to the above, the third main way in which this research is novel is that the effects of feedback were neither mediated by medical consultation processes nor by healthcare professionals. Previous studies have been contextualised in medical settings

and as such have been unavoidably mediated by clinical care practices. Indeed, a number of the studies have been concerned specifically with the incorporation of feedback mechanisms into routine clinical care with delivery by healthcare professionals (Hilarius et al., 2008; Santana et al., 2010; Velikova et al., 2008; Velikova et al., 2004; Velikova et al., 2010). The research undertaken in the present programme of research was conducted outside of a medical setting and was implemented in a community sample, with feedback administered and delivered by a non-medical researcher to participants in their own homes. This approach was taken in order to try to understand the effects of feedback without the influence of any particular context.

Fourthly, most previous studies have used oncology patients as their study samples. Although there are exceptions (De Wit et al., 2008; De Wit et al., 2010; Gutteling et al., 2008; Santana et al., 2010), the primary focus has been on feedback of QoL to patients living with, or recovering from, various cancers. In this study the effect of the feedback process for those with chronic illnesses was investigated, with a healthy comparison group. Prior research has suggested that self-management interventions can have a positive effect in chronic illnesses and this suggests a potential avenue for the future application of this research (Ditewig, Blok, Havers, & van Veenendaal, 2010; Labrecque et al., 2011).

Finally, no studies exist that have investigated the effects of QoL feedback on QoL-related goal orientation. Given that the importance of goals is fundamental in SRT, it was decided that to include this in the study might add valuable insight into the practical effects of a QoL feedback intervention.

The primary research question for this study was:

What impact does completing and receiving structured feedback on their subjective ratings of QoL and the importance they attach to its various aspects, have on an individual's consideration of his/her QoL-related goal orientation, QoL, and mood?

In addition, a secondary research question was addressed:

Does receiving verbal guidance to review the feedback affect consideration of QoL-related goal orientation, QoL and mood differently from following written instructions?

5.1.2 Hypotheses

It was hypothesised that the strategic use of QoL feedback, as the basis of a theoretically-driven intervention, would be associated with improvements in individual's later self-ratings of their QoL, their emotional state, and their QoL-related goal orientation. The specific hypotheses that related to the research questions above were:

- *Hypothesis 1:* Receiving individualised guided feedback on subjective QoL and importance judgements will be associated with improvements in subsequent subjective ratings of QoL, mood and QoL-related goal orientation.

This hypothesis was adapted and extended from previous findings that completion of QoL measures and subsequent feedback led to improvements in emotional wellbeing (Velikova et al., 2004) and in psychosocial and mental health (De Wit et al., 2008).

- *Hypothesis 2:* Receiving verbal guidance to review the feedback will have a stronger association with improvements in QoL, mood and QoL-related goal orientation, than receiving written instructions for self-reviewing feedback.

This hypothesis was based on previous finding that indicated most patients want to discuss their QoL (Detmar et al., 2000). Whilst, as discussed previously, a few studies have investigated patients preferences for various visual and written formats for communicating QoL information (Brundage, 2002; Brundage et al., 2005; Brundage et al., 2003), no previous studies were have investigated the differential effects of verbal guidance of QoL feedback versus written instructions for self-review of QoL feedback.

5.2 Method

5.2.1 Study design

This study applied a concurrent nested design with a mixed methods strategy (Bowling & Ebrahim, 2005). In this design baseline quantitative data were collected at T1 (pre-test). Following the feedback intervention T2 (post- test) data were collected and T3 questionnaire completion (post-study evaluation of change) immediately followed.

Quantitative data at T1 and T2 examined the primary outcomes of health status, mood and QoL-related goal orientation. Other outcomes of QoL and the importance of its various facets were considered to be supplementary, as these also provided the basis of the feedback mechanism in the study. These measures were discussed in detail in Chapters 3 (WHOQOL instruments) and 4 (EQ-5D, PANAS & GOSS-Q).

Subjective perceived changes in QoL were elicited using transition questions contained in the post-study evaluation of change questionnaire at T3. These questions were similar to those used in the previous study and again were intended to assess perceived rather than measurable changes against which to interpret the quantitative data.

Participants were recruited to provide a community sample that was primarily composed of people with a chronic physical health condition but which also included a healthy comparison group. The target sample was designed to be 70% chronically ill, 30% healthy with the sub-samples being broadly comparable in terms of proportions of participants in each of these groups within each experimental condition. Furthermore recruitment of the chronic illness cohort was intended to include participants with a range of chronic health conditions, as specified by the International Classification of Disease categories (World Health Organization). These conditions were: a) circulatory system (chronic heart disease; heart failure; stroke & transient ischemic attack; hypertension; and atrial fibrillation, b) endocrine, nutritional and metabolic (diabetes; hypothyroidism; and obesity, c) respiratory system (chronic obstructive pulmonary disease, asthma and chronic bronchitis or emphysema), d) genitourinary (chronic kidney disease); e) dermatological (eczema); nervous system (multiple sclerosis and epilepsy).

5.2.2 *Sample inclusion & exclusion*

For the purposes of the study, participants were defined as chronically ill if they stated that they had been diagnosed with a physical illness for 12 months or more. This approach was adopted as participants were asked to indicate how long ago they were diagnosed according to specific categories (less than 1 month, 1 -12 months, 1 year, 2 years, 3 years etc.) As no 3 month or 6 month category was included, participants with an illness diagnosed 1 or more years ago were therefore categorised as chronically ill. Those with a chronic illness diagnosed less than 12 months previously were included in the healthy comparison group.

The study rationale and research questions related to using QoL information within physical healthcare, rather than in mental health settings, as it was a concern that responses from individuals whose primary healthcare condition was psychiatric in nature might demonstrate different perceptions and priorities to those without mental health problems. The study did not therefore seek to recruit adults with diagnosed chronic mental health difficulties as a specific chronic illness group.

All participants were required to give their full informed consent to taking part, were over 18, literate, and able to comprehend and communicate sufficient English to understand the information they were given and to complete the questionnaires independently. Literacy and understanding was assessed from participants' written communications, including responses to open-ended questions, and from telephone conversations.

Ethical approval for the study was granted by the University of Bath, Department of Psychology Research Ethics Committee, and by the NHS South West 5 Research Ethics Committee. All participants were assured of the confidential handling of any information supplied and that, upon recruitment into the study, each individual would be allocated a unique reference number so that their data could be used anonymously. It was made clear at the outset that those who chose to take part would be randomly allocated either to receive written instructions or verbal guidance to review feedback on their subjective judgements of QoL.

5.2.3 *Sample recruitment*

To achieve a sample of participants with a range of chronic illnesses, sampling was purposive in two recruitment phases. In Phase 1 of recruitment, notices about the study were posted on the websites of the MS Society, Asthma UK (who also emailed their research group members), the National Eczema Society (with notification in their magazine), Epilepsy Action. Details of the study were also circulated by the British Lung Foundation to their “Breatheasy” support groups. These notices explained that both individuals with chronic physical illnesses and healthy adults were sought for the study. A further sample of chronically ill and healthy adults was also recruited at the University of Bath through email and posters, and advertising at a well-being fair for university staff. Recruitment at the university primarily targeted postgraduate students and staff in order to try to achieve a homogenous sample with regard to age, although undergraduate students and secondary contacts were also accepted into the study if they met the inclusion criteria.

As insufficient numbers of participants were recruited via the charity websites, a second phase of recruitment approached patients more directly, via Yatton Keynell Surgery - a local Wiltshire General Practitioner (GP) practice, which operated as a Participant Identification Centre. Using a quota sampling strategy for chronic illnesses, potential participants were identified by the Practice Manager from a search of patient records and invited to take part by letter from their GP.

5.2.4 *Procedure*

Details of all the questionnaires and measures are given in section 5.2.5. All were administered either a) online via the Bristol Online Survey service (BOS), or b) in paper format by post.

In Phase 1 of recruitment potential participants made contact with the University by email. Their interest was subsequently acknowledged and they were sent links to an online welcome page giving full participant information and a set of consent statements and to the T1 set of online questionnaires. In the Phase 2, participants were invited to either a) access the online survey; or b) to complete and return a reply slip to receive a paper version of the first set of questionnaires. The participant information sheet is given

in Appendix Q. (Recruitment phases were described in more detail in section 5.2.3 above.)

Participants were firstly asked to complete the T1 set of questionnaires. From these the graphical summary profile for individualised feedback for each participant was generated from the responses to the WHOQOL instruments. (The graphical summary profiles were previously described in detail in Chapter 3, section 3.2.1.2). Within 1 – 3 weeks of T1, participants took part in a structured and guided feedback process regarding their responses, the protocol for which was specific to one of the two experimental conditions (see below). More detail regarding the feedback processes itself is given below. For those participants whose feedback guidance was by telephone, additional verbal comments were manually recorded during the conversation.

Participants were asked to complete the T2 questionnaire as soon as possible after the feedback intervention, and to follow this with the T3 questionnaire (again preferably on the same day, or as soon as was practicable thereafter). Debriefing information was included at the end of the T3 questionnaire for the online participants and a post-study summary of results was offered to those completing the paper version.

Experimental conditions

Participants were allocated to one of two modes of feedback administration by stratified randomisation using random numbers tables generated by the Research Randomiser website: www.randomizer.org. On recruitment into the study, participants within the chronic physical illness group and within the healthy group were randomised to the feedback conditions separately, to ensure balance both within and between each group in relation to mode of feedback. The two modes of feedback administration were: 1) verbal guidance; and 2) written instructions. In both modes participants were asked to refer to the personal graphical summary profiles of their scores on the WHOQOL instruments, which they had been sent as feedback. In the first condition, while participants viewed their graphical summary profiles, they received verbal guidance over the telephone according to a pre-defined script. The guidance was given by the author of this thesis and provided participants with directions for inspecting their subjective QoL judgements (verbal guidance group). In the second condition participants were simply asked to review their individualised graphical summary profiles by following a set of written

instructions (written instructions group). The presentation and design of the graphical summary profiles was identical for both conditions. The procedures followed in each of the experimental conditions are elucidated below.

5.2.4.1 Experimental conditions: verbal guidance vs. written instructions:

The protocols for the both the verbal guidance group and the written instructions group were developed from the findings of Study 1. As seen earlier, this prior study had explored the feedback methodology and had asked participants for reflexive feedback on the protocol employed. Consequent refinements were then incorporated into the feedback protocols of Study 3.

The protocol for interpretation of the graphical summary profiles (whether by following the written instructions or during verbal guidance) was intended to focus participants' attention to specific areas and particularly to where there were differences (termed "gaps" to participants) between their QoL scores and their respective Importance ratings. The instructions were also deliberately designed to end by focusing on positive aspects of QoL. Both protocols were designed to mirror one another in terms of instructions regarding the steps to be followed in viewing the graphs, which specific aspects should be looked at, and the questions participants should reflect on. The written instructions and verbal guidance "script" used each of the conditions respectively are given in Figures 5.1 and 5.2 and elucidated below.

In both conditions, participants' attention was firstly directed to a graph illustrating their domain scores, explaining that these scores indicated how they rated broad aspects of their QoL, e.g. overall physical health. While reviewing this graph the presentation format was explained, i.e. that blue bars represented QoL scores and red triangles represented the participant's rating of importance for that aspect. The range of possible scores was pointed out (0-100) and it was explained that scores above 50 meant good QoL or high importance.

Participants' attention was then directed to the remaining graphs in the graphical summary profile, explaining that these showed their ratings of individual aspects. Again the range of scores was firstly explained: when they completed the questionnaire they

could score from 1-5, but a zero was included on the graph scale so that participants could see where they had missed a question. Participants were then asked to look at each graph in turn: Physical Health, Psychological Health, Social Relationships and Environment.

In the written instructions group, participants were asked look at the graphs and to identify: a) where QoL was rated 4 (good) or 5 (very good), b) where they could see big gaps between the QoL and importance ratings, and c) where both QoL and importance were rated high. The verbal guidance followed the same format but the identification of the above was completed by the researcher and communicated to the participant during the guidance (i.e. they did not have to identify the points for themselves).

Participants in both conditions were instructed that those aspects which they had rated as poor but important were areas where they may want to think about what they might be able to do to make these gaps smaller. A number of questions were also posed to participants in both conditions a) “What in the graphs particularly stands out for you?”, b) “What about the graphs is relevant for you at this point in time?” and c) “What have you learned from looking at these graphs?”

Although each experimental condition was designed to ensure participants attended to their graphical summary profiles in the same way, the verbal guidance condition allowed participants to ask questions if they required immediate clarification. It was made clear in correspondence with participants in the written instructions condition that they were welcome to contact the researcher if they had any questions or needed any help, however none did so.

Early piloting of Study 3 identified a number of additional refinements to the verbal feedback protocol. These were primarily to accommodate those instances where a number of facets clearly grouped together as these patterns were likely to be spontaneously recognised. For example, where all facets within a domain were rated as good or very good, it was found to be more appropriate to verbalise this group pattern (e.g. “*you rated all QoL scores in this domain as good or very good*”) than to list each item separately. Similarly, to avoid the tedium of repetitions, alternative wording was

Figure 5.1 Written instructions for how to read and interpret the graphical summary profile





<div data-bbox="526 406 748 477">  <p>WHO Field Centre for the study of quality of life</p> </div> <div data-bbox="936 406 1072 477">  <p>UNIVERSITY OF BATH July 2010 Study 3</p> </div> <p>How to read the feedback graphs</p> <p>Thank you for taking part in this study. The graphs you have been sent give you your personal feedback by showing how you rated each question in the World Health Organisation questionnaires.</p> <p>There were questions about many aspects of quality of life. The facet sheet you were also sent shows you how all these aspects fit together. For example, questions about pain, sleep and mobility all fit into your physical health; questions about your feelings and your self esteem fit into your psychological health and so on.</p> <p>Please note that these graphs show only the information that you gave regarding your own quality of life. They do not show anyone else's answers.</p> <p>To help you understand the graphs, here is some guidance to assist you as you read.</p> <p>Step 1</p> <ul style="list-style-type: none"> Firstly, look at your graph at the top of graph page 1, called "Domain Scores". The bars show you how you rated the broad aspects of your quality of life, for example, overall physical health. The triangles show you how important you rated these aspects to be to you. <p>Important points:</p> <ul style="list-style-type: none"> The scores on these graphs range from 0 – 100. Scores above 50 mean good quality of life or high importance. Scores below 50 mean poor quality of life or low importance. <p>Step 2</p> <ul style="list-style-type: none"> Now look at your other graph on graph page 1, called "Overall Quality of Life and Health". This shows you how you rated your quality of life and health in general and the importance ratings you gave to these aspects. <p>Important points:</p> <ul style="list-style-type: none"> The scores on these graphs range from 1 – 5 as follows: <table border="0"> <tr> <td><u>Quality of Life (bars)</u></td> <td><u>Importance (triangles)</u></td> </tr> <tr> <td>1 = very poor</td> <td>1 = not important</td> </tr> <tr> <td>2 = poor</td> <td>2 = a little important</td> </tr> <tr> <td>3 = acceptable</td> <td>3 = moderately important</td> </tr> <tr> <td>4 = good</td> <td>4 = very important</td> </tr> <tr> <td>5 = very good</td> <td>5 = extremely important</td> </tr> </table> <p style="text-align: right;">Please turn over</p> <p style="text-align: center;">1</p>	<u>Quality of Life (bars)</u>	<u>Importance (triangles)</u>	1 = very poor	1 = not important	2 = poor	2 = a little important	3 = acceptable	3 = moderately important	4 = good	4 = very important	5 = very good	5 = extremely important	<div data-bbox="1303 406 1525 477">  <p>WHO Field Centre for the study of quality of life</p> </div> <div data-bbox="1706 406 1843 477">  <p>UNIVERSITY OF BATH July 2010 Study 3</p> </div> <p>Step 3</p> <ul style="list-style-type: none"> Now look at your graphs on pages 2 and 3 called "Physical Health", "Psychological Health", "Social Relationships" and "Environment". These graphs show the responses you gave for the more detailed aspects of your quality of life. <p>Important points:</p> <ul style="list-style-type: none"> As in Step 2, the scores on these graphs range from 1 – 5 as follows: <table border="0"> <tr> <td><u>Quality of Life (bars)</u></td> <td><u>Importance (triangles)</u></td> </tr> <tr> <td>1 = very poor</td> <td>1 = not important</td> </tr> <tr> <td>2 = poor</td> <td>2 = a little important</td> </tr> <tr> <td>3 = acceptable</td> <td>3 = moderately important</td> </tr> <tr> <td>4 = good</td> <td>4 = very important</td> </tr> <tr> <td>5 = very good</td> <td>5 = extremely important</td> </tr> </table> <p>Step 4</p> <p>Looking at all your graphs on pages 2 and 3, please consider the following questions:</p> <ul style="list-style-type: none"> Where have you rated your quality of life (bars) as 4 = good, or 5 = very good? Where can you see big gaps between your rating of quality of life (bar) and importance (triangle)? <p><i>For those aspects where you rated your quality of life as poor or very poor but these aspects are very or extremely important to you, you may want to think about what you might be able to do to make these gaps smaller.</i></p> <ul style="list-style-type: none"> For which aspects have you rated BOTH your quality of life AND importance to be high? <p>Step 5</p> <p>Finally, please consider these questions:</p> <ul style="list-style-type: none"> What in the graphs particularly stands out for you? What about the graphs is relevant for you at this point in time? What have you learned from looking at these graphs? <p>Please note, if you see a zero for any aspect of any graph, this means that that particular question had not been answered.</p> <p>I hope that this guidance helps you to understand your graphs. Thank you.</p> <p style="text-align: center;">2</p>	<u>Quality of Life (bars)</u>	<u>Importance (triangles)</u>	1 = very poor	1 = not important	2 = poor	2 = a little important	3 = acceptable	3 = moderately important	4 = good	4 = very important	5 = very good	5 = extremely important
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Figure 5.2 Verbal script to provide guidance in reviewing the graphical summary profiles

WHO Field Centre
for the study of quality of life

Participant id

Quality of Life Study 3 – Telephone feedback – notes

Date Time

Is it convenient to talk now?
Have you printed the graphs and the facet sheet or can you view them as we talk?
Do you have them in front of you now?

Introduction

The graphs give you your personal feedback showing how you rated each question in the WHOQOL-BREF questionnaire.

There were questions about many aspects of quality of life. So if you look at the facet sheet, this shows you how all these aspects fit together. For example, questions about pain, sleep and mobility all fit into your physical health; questions about your feelings and your self esteem fit into your psychological health and so on.

Please note that these graphs show only the information that you gave regarding your own quality of life. They don't show anyone else's answers.

Domain scores

Firstly please look at the graph at the top of page 1, called "Domain Scores". The bars show you how you rated the broad aspects of your quality of life to be, for example, overall physical health. The triangles show you how important you rated these aspects to be to you.

The scores on this graph range from 0-100. Scores above 50 mean good quality of life or high importance. Scores below 50 means poor quality of life as poor or low importance.

(Pick an example.) So for the bar here, a score above 50 means that you view your quality of life as good or very good and an importance triangle above 50 means that you feel this to be very important to you.

So for the domains:
Aspects you rated as of low importance were and of poor QoL were

Aspects you rated as of high importance were and of good QoL were

Facet scores

Now please look at the other graph on page 1, called "Overall Quality of Life and Health". This shows how you rated your quality of life and health in general and the importance rating you gave to those aspects.

The scores on this and the rest of the graphs range from 1 – 5 where a bar of 1 is very poor quality of life and a bar of 5 is very good quality of life. Similarly for the triangles, 1 indicates a rating of not important and 5 indicates extremely important. So you rated ... (Make comment on results)

Now I'd like you to look at the responses you gave for the more detailed aspects of your quality of life. Please could you look at pages 2 and 3.

a) QoL = 4 or 5
So, looking at the graphs on pages 2 and 3, you rated your QoL as good or very good in relation to:
.....
.....
.....
.....
.....

b) Where QoL and Importance gap ≥ 2)
For some facets it is interesting that there is quite a gap between how you rated your quality of life and how you rated importance. You can see that these facets were:
.....
.....
.....
.....
.....

c) Where QoL = 4 or 5 AND importance = 4 or 5
On a positive note, you rated both your quality of life AND its importance to be high for:
.....
.....
.....
.....
.....

This suggests you are satisfied in (all) these areas and that they meet your expectations.

Overall considerations

Now you have looked at the graphs in some detail, I have some final questions for you:

1. Firstly, what on the graphs particularly stands out for you?

2. What else about the graphs is relevant for you at this point in time?

3. Finally, what have you learned from looking at the graphs?

If multiple within a domain say "Other than x, you rated your qol as good for all the facets in the x domain"

incorporated to accommodate multiple instances of similar QoL-Importance differences (e.g. good QoL and low Importance). Although these refinements were applied to the verbal script, the instructions for the written instructions group did not require any amendment as the written instructions would have already enabled participants to identify these types of patterns for themselves. Neither did any participant ask for clarification of the instructions. Further details regarding the procedures used in the administration of each condition are given below.

Written Instructions Group Administration

Within one week of receipt of their first set of completed questionnaires, those participants receiving written instructions were sent their individualised graphical summary profile (by first class mail or email) along with a WHOQOL diagram showing how the different facets and domains of QoL are structured within the WHOQOL-BREF model (as shown in Chapter 3, Figure 3.4). The covering letter is given in Appendix R, and this wording was also used where graphical profiles were sent by email. Enclosed with the letter were the written instructions on how to read and interpret the graphical summary profile (as were shown above in Figure 5.1).

Participants were asked to individually inspect the profile by following the instructions as closely as possible. Accompanying the profile, participants in the written instructions group were also sent the T2 set of questionnaires with directions for its completion after they had looked at the graphical summary profile according to the instructions given. They were also asked not to refer back to their graphical summary profiles when completing the second set of questionnaires. The T2 set of questionnaires was again administered online or on paper, replicating the T1 set.

Verbal Guidance Group Administration

On receipt of their T1 set of questionnaires, those participants allocated to the verbal guidance group were contacted by email or telephone to arrange a convenient time within the next week when they would be available to discuss their graphs. Once an appointment had been mutually agreed, their individualised graphical summary profiles were sent with a covering email, or letter of instruction (also shown in Appendix R). These were sent so they would arrive 1-2 days prior to the feedback appointment. Prior to the call, the researcher inspected the participant's profile and completed a guidance

script pro-forma. This formed the verbal protocol to be followed in the subsequent discussion as was discussed earlier (given in Figure 5.2). Before the telephone appointment, participants were asked to have their graphical summary profile in front of them and this was referred to throughout the guidance conversation. On completion of the guidance, participants were thanked verbally and asked to complete the T2 set of questionnaire as soon as possible (online or on paper). Again they were asked not to refer back to the graphical summary profile while they completed the T2 questionnaires.

For two participants, a different protocol for verbal guidance was developed. The graphical summary profiles of these cases clearly indicated they considered themselves to have very poor QoL in a number of areas. As they had opted to take part, it was decided that feedback was should still be given, but that a different approach would be more appropriate. This was intended to minimise any possible detrimental effects that could potentially result from pointing out poor QoL to an individual who might already be psychologically vulnerable. An alternative protocol was therefore developed which highlighted those areas that were relatively less poor, while still acknowledging the very poor QoL in other areas. It was also decided that the protocol should be adjusted to make it clear that some areas of QoL, particularly in relation to physical health, might be out of the individual's control, and therefore not something that they should necessarily seek to change. For example, a high dependence on medication for a health condition would result in a poor QoL score for this facet, yet the individual's prescribed treatment regime should not be amended without clinical consultation. An example of the alternative protocol adopted for one of these cases is given in Appendix S.

5.2.5 *Measures*

All data collection was by completion of Likert scales, multiple choice questions or open-ended questions. The T1 measures were employed to capture participants' subjective ratings of mood (PANAS) (Watson et al., 1988), health-related QoL (EQ-5D) including its VAS (The EuroQoL Group, 2010) and QoL-related goal orientation (GOSS-Q) (Yardley & Dibb, 2007). Details of the PANAS and GOSS-Q scales were given previously in Chapter 4, section 4.2.4. The WHOQOL-BREF and WHOQOL Importance Questionnaires were also included, both as supplementary outcome

measures and to provide the mechanism for QoL feedback. Details of both these measures were given earlier, in Chapter 3, section 3.2.1.

A number of additional questions were also included at T1 to obtain socio-demographic data. These questions explored age, gender, education level, ethnic origin, marital status, living arrangements, location of home, present or most recent occupation and employment status, subjective financial status, and health status. Also included was a checklist of health conditions through which participants could indicate co-morbidities, identify which condition they felt had most effect on their QoL, and specify how long they had had this condition. These additional questions are shown in Appendix T.

For this study the version of the EQ-5D employed was the newly available EuroQoL 5 level version (The EuroQoL Group, 2010) which asks participants to indicate no problems, slight problems, moderate problems, severe problems, or an inability to complete dimension related tasks. A copy of this new version is given in Appendix U.

The T2 set of questionnaires repeated the measures contained in T1, but without the demographic and health condition questions. A number of transition questions were also included in the second questionnaire pack as post-study evaluation of change – T3 (see Appendix V). This T3 questionnaire was based on the same format as had been used in Study 2 and again sought to investigate individual's experiences of the study process, including their subjective views on how they believed their participation may have affected their QoL or the ways in which they thought about it. Again responses were recorded on Likert scales, as well as through the provision of additional explanatory comments. Participants were asked whether their participation had affected their plans or expectations for the future, and whether they thought any changes had resulted from taking part in terms of their physical health, psychological health, social relationships or environment. They were also asked how helpful they thought their experience of the study would be in the future. For monitoring purposes, participants were finally asked to indicate how they had heard about the study and why they had been interested to take part.

5.2.6 *Data preparation*

Raw data collected electronically from the online completion of the questionnaires were exported into Microsoft Excel and copied into SPSS. Data collected from the paper questionnaires were entered manually. Total scores were calculated for each participant for the PANAS positive and negative affect items and for the GOSS-Q. Details of the scoring of these measures were given earlier in Chapter 4, section 4.2.4.

As described in Chapter 3, section 3.2.1, the three negatively framed items in the WHOQOL-BREF core data were reversed and all the data then transformed to produce domain scores on a 1-100 scale using an SPSS syntax file from the WHOQOL Group (<http://www.bath.ac.uk/whoqol/>). A new syntax file was written in SPSS for this study, to similarly transform the WHOQOL Importance scores. This was based on the WHOQOL-BREF syntax but there were no negatively framed items to reverse. A copy of this new syntax is given in Appendix W.

Prior to analyses, the main outcome variables were examined for accuracy of data entry, missing values and extreme scores (Tabachnick & Fidell, 2001). Where data were missing from the WHOQOL-BREF core and importance scales, the transformation syntax providing the domain scores also included algorithms to replace missing values with mean values for that participant calculated from the remaining items completed in each domain (subject to the prescribed minimum numbers of items being completed). Following an approach advocated by Amiot, Gaudreau and Blanchard (2004), missing values found within the other scales (PANAS and GOSS-Q) were replaced with values imputed from the mean self-ratings provided by that participant on that scale. However, this imputation was only carried out where no more than 1 item was omitted by a participant within the scale in question, to avoid distortion of scores. This criterion was applied in line with the recommendation of Tabachnick and Fidell (2001) that substitution should only be used when the proportion of missing scores is very small. For no participant were values imputed for more than 2 items out of a total 26 possible items across the PANAS and GOSS-Q scales. Missing EQ-5D VAS data were unchanged.

Examination of standardised scores for values within all the measures revealed a number of extreme scores on a range of variables. Where outlying scores were outside the range

$z = \pm 3.29$ this was adjusted to one unit less/more than the next lowest/highest case (Dancey & Reidy, 2004; Tabachnick & Fidell, 2001). Adjustment of scores was applied in this way to 10 scores within the total data set (from 7 cases). One case that represented a particularly low score (1) on the WHOQOL-BREF general QoL item at T1 was left unchanged as the next lowest case was only 1 unit above. The score for one participant on the EQ-5D VAS that was extreme was removed. Other cases were checked for unusual features and were retained in the analysis unchanged.

Normality indices showed appropriate levels of skewness and kurtosis for most variables given the sample size, and these were within the recommended range of ± 1 (Hair et al., 1999). However, skewness and kurtosis for the total values of the Negative Affect scale of the PANAS were problematic. Skewness was 1.7 at T1, and 2.0 at T2; kurtosis was 2.7 at T1, and 3.6 at T2. Following Field (2005) logarithmic, square root and reciprocal transformations were applied. The reciprocal transformation had the effect of bringing the negative affect data within the ± 1 range, and was consequently retained.

5.2.7 Data analysis

Quantitative data were analysed using SPSS v18. Prior to testing the hypothesised relationships inferentially, descriptive statistics of the variables were produced using data provided by those participants who completed both the T1 and T2 questionnaires. Scores from those participants who completed T1 questionnaires but failed to return completed T2 questionnaires were excluded from the analysis, in case this group differed in terms of characteristics. However these data were used in later analyses, as will be shown in Chapter 6.

Factorial repeated measures analyses were used to examine main effects and differences between groups. In each analysis the within-subjects variable was time (T1 – T2), and health status (chronically ill or healthy) and experimental condition (verbal guidance or written instructions) were included as between-subjects factors. Including all the dependent variables (DVs) in a single MANOVA was initially considered, however Field (2005) asserts that this approach should only be used when there is a good theoretical or empirical basis for doing so. Furthermore, Tabachnick and Fidell (2001, p. 268) point out that “*MANOVA works best with highly negatively correlated DVs and*

acceptably well with moderately correlated DVs in either direction". Tabachnick and Fidell (2001) also suggest that MANOVA is considered inappropriate if dependent variables are uncorrelated. Following this guidance, the WHOQOL-BREF domains were examined together in one MANOVA analysis, along with the EQ-5D VAS which correlated moderately with most of the WHOQOL-BREF domains. Individual repeated measures ANOVAS were used to examine the remaining DVs: GOSS-Q, PANAS positive affect and PANAS negative affect, as each of these was mostly only weakly correlated with the other DVs. The WHOQOL-Importance domains were analysed in a separate MANOVA, as the domains in this scale were correlated with one another but were largely uncorrelated with all the other DVs.

Throughout the analyses Bonferroni corrections were applied to ensure that the cumulative Type 1 error remained below .05 throughout (Field, 2005). Sphericity was not a concern as there were only two levels in the within-participants variable (T1 and T2), nevertheless Greenhouse-Geisser adjustments factors were applied as these are considered to make testing more stringent (Dancey & Reidy, 2004). Assessment of effect size was calculated using J. Cohen's (1988) guidelines for the interpretation of F , and equivalent values of partial eta squared (η^2), whereby $0.01 \leq \eta^2 < 0.06 = \text{small}$; $0.06 \leq \eta^2 < 0.14 = \text{medium}$; and $\eta^2 \geq 0.14 = \text{large}$ (Kinnear & Gray, 2010)

Multiple regression analyses were conducted to investigate potential predictors of the any changes in QoL over time for those measure(s) in which a significant variance between T1 and T2 had been found. (The amount of change between T1 and T2 was calculated for the scores of each participant and used as the dependent variable (Field, 2005). In the first regression demographic variables were investigated using dichotomised categories (as is necessary for the inclusion of categorical variables as independent variable in multiple regression). Age was dichotomised to 18-44 years and 45+ years, as these categories have been typically used in psychometric analyses of the WHOQOL instruments (Skevington, 1999; Skevington, Lotfy, et al., 2004; Skevington & O'Connell, 2004; The WHOQOL Group, 1998a). Gender and whether participants had a chronic illness or were healthy were also included in the same analysis. In a second regression analysis baseline (T1) scores from the primary outcome measures of the PANAS (total positive and total negative affect), the EQ-5D VAS and the GOSS-Q were simultaneously entered into the regression model.

In interpreting these regressions the value of “adjusted r^2 ” was used in order to eliminate positive bias in the estimate of the amount of variance (Dancey & Reidy, 2004; Kinnear & Gray, 2010). J. Cohen’s (1988) classification of r^2 was used to determine effect size whereby $0.01 \leq r^2 < 0.09$ = small; $0.09 \leq r^2 < 0.25$ = medium; and $r^2 \geq 0.25$ = large.

The study feedback methodology asked participants to consider the differences between their WHOQOL-BREF “core” scores and their associated WHOQOL Importance scores. Whilst both the WHOQOL-BREF and WHOQOL-Importance were derived from a common QoL stem and individual items are measured on 5-point scales in both instruments, this does not imply they use the same metric as they measure different constructs (i.e. a score of 75 on QoL for a particular facet is not necessarily the same as a score of 75 on Importance for that facet). However, it was felt appropriate to examine the differences between scores on each measure to identify variances between them at T1 and at T2, as well as to consider the magnitude of the variances in terms of possible change over time. Dependent t tests were used for these exploratory analyses.

T3 questionnaire data were initially analysed to determine the frequencies of categorical responses to the transition questions, with re-coding applied where necessary to create useful dichotomies e.g. those reporting change versus no change. Non-parametric tests (one-sample binomial and Chi square) were used to determine differences between observed and expected frequencies within the categorical data and to test associations between variables. Effect sizes for the binomial tests were calculated from J. Cohen’s g (1988). This gives g as the difference between P , (the proportion of outcomes in the target category and p , the probability of the outcome under the null hypothesis. It suggests that values of <0.05 , $.05$, $.15$ and $\geq .25$ can be interpreted as trivial, small, medium, and large effects respectively. Similarly, where applicable, effect sizes for Chi-square goodness of fit analyses were calculated using Cohen’s w whereby $<.3$, $<.5$, and $\geq .5$ are small, medium and large effects (Kinnear & Gray, 2010).

Following the methodological guidance of Donovan and Saunders (2005) qualitative data were transcribed, sorted by question, and then coded in two stages. Stage one was an interpretation of the general sense of each statement and an identification of themes. The themes were then organised into a framework (see Appendix X), according to which the data were subsequently re-coded in the second stage of analysis. By applying a

concurrent embedded strategy the qualitative work was intended both to explain and interpret the quantitative results and to provide additional insights for discussion (Creswell, 2009).

5.3 Results

5.3.1 Sample

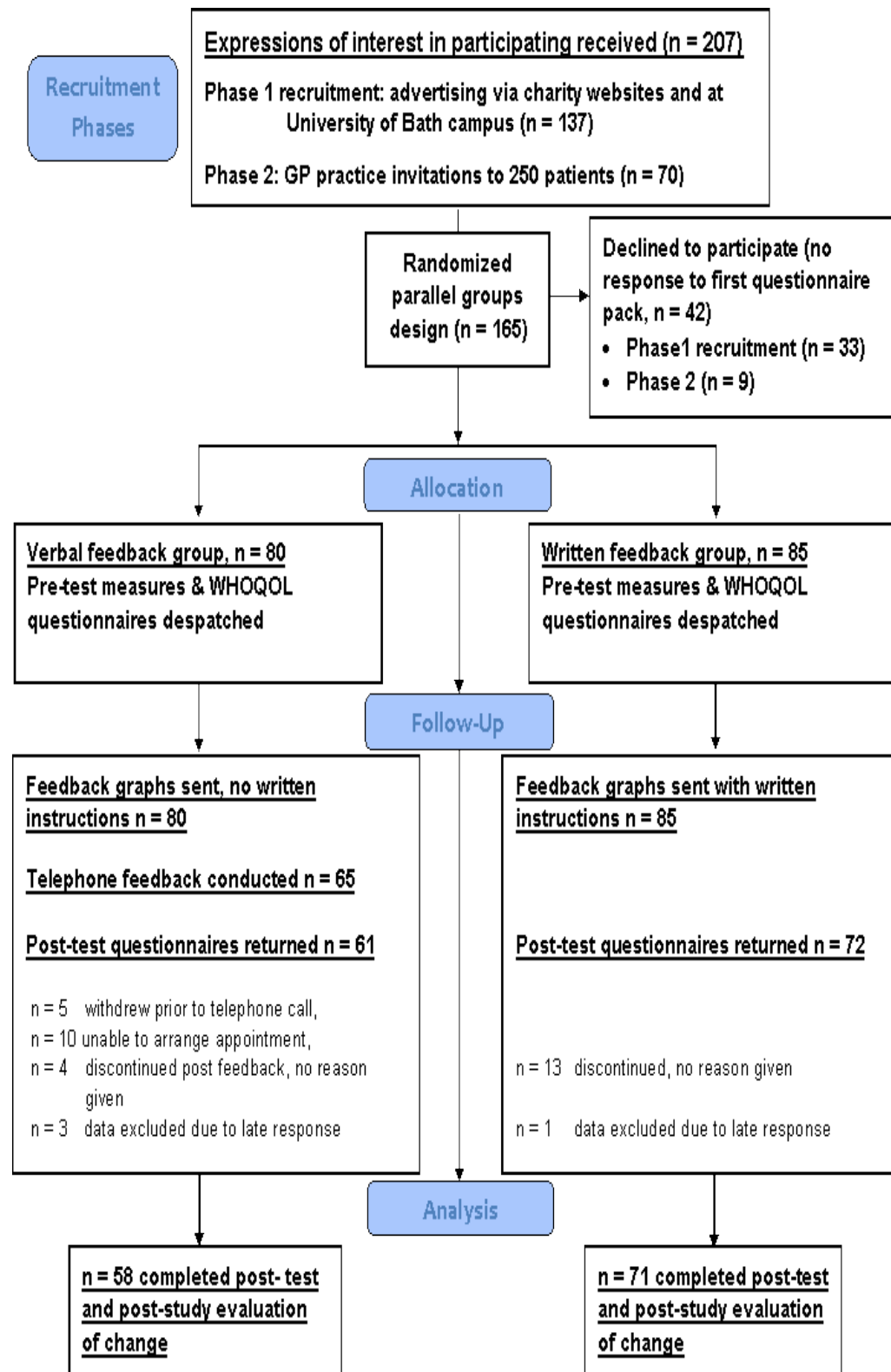
In the Phase 1 of recruitment, 104 participants responded to the charity website advertising, making contact by email to express interest in the study. Of these 87 (84%) subsequently went on to take part. An additional 33 potential participants responded to advertising at the University of Bath, giving their email details to receive further information. Of these, 16 did not subsequently complete any of the questionnaires (an attrition rate of 48%).

In the second phase of recruitment, 250 potential participants were contacted by their GP to invite them to take part. Responses were received from 70 individuals (a response rate of 28%) and, of these, 61 (87%) went on to participate in the study. The majority of these ($n = 56$) chose to complete paper questionnaires, whilst 5 participants opted to complete the questionnaires online. Figure 5.3 illustrates the study phases and attrition statistics in a consort diagram.

The initial sample therefore contained 165 participants at T1, and 129 (78%) of these also completed the second set of questionnaires - an attrition rate within the study of 22%. A more detailed analysis revealed that attrition was similar for males and females (25%) and females (20%) and neither did attrition vary markedly across most age bands. However, of those initially recruited into the study, only 74% in the chronically ill group completed both sets of questionnaires as opposed to 87% of participants in the healthy comparison group.

Socio-demographic data were collected from all participants for later analyses of covariates of the main effects, but were not relevant in terms of inclusion or exclusion criteria at the time of recruitment nor to allocation to experimental condition groups.

Figure 5.3 Study phases and attrition



The final participant sample consisted of 129 people, 84 (66%) females and 44 males (34%). One participant chose not to disclose their gender. Age data were collected according to predefined categories (18-24; 25-34 etc.). Ages of participants according to these categories are given in Table 5.1.

The full demographic details of the sample are also given in Table 5.1. The majority of participants (64%) had received a college, university or postgraduate education. Of sample, 96% described themselves as white, 0.8% as Indian, and 0.8% as Chinese. Just over half the sample (52%) were married, 76% were living with a spouse, partner or family when they completed the questionnaires, and almost half (48%) described their place of residence as in the suburbs, with 31% residing in the countryside and 21% in the centre of a town or city. A little over a quarter of participants (28%) were retired, 34% were employed full-time, and 12% were employed part-time.

Of the total sample 85 (66%) were categorised as chronically ill, and 44 (34%) as healthy, or not having had an illness or disease of at least 12 months' duration. Of those categorised as chronically ill, five participants reported that the chronic condition with which they lived, and which most affected their QoL, was depression and/or anxiety. However, given these participants also had chronic physical health co-morbidities and were only a small proportion of the total sample, it was decided that, these participants should not be excluded from the study. Purposive recruitment had otherwise resulted in a heterogeneous sample across a variety of physical chronic illness conditions. Further details of the health conditions within the sample of chronically ill respondents are given in Table 5.2.

As shown earlier in Figure 5.3, of the 129 participants who completed both sets of questionnaires, $N = 71$ (55%) were in the written instructions condition and $N = 58$ (45%) received verbal guidance. Within this, 54% ($N=46$) of the chronically ill participants, were in the written instructions condition and 46% ($N=39$) in the verbal guidance condition. Of the healthy participants 57% ($N=25$) were in the written instructions condition and 43% ($N=19$) were in the verbal guidance condition. Equal balance was not fully achieved due to attrition post allocation and also because the random numbers table used was based on a larger sample population than proved practical to recruit.

Table 5.1 Demographic characteristics of Study 3 participants

		<i>N</i>	% of total sample (<i>N</i> =129)
Age	18-24	11	8.5
	24-34	17	13.2
	35-44	18	14.0
	45-54	24	18.6
	55-64	24	18.6
	65-74	19	14.7
	75+	13	10.1
	Not disclosed	4	3.1
Education	Primary	1	0.8
	Secondary	23	18.1
	Technical / Further Education	21	16.5
	College / University	32	25.2
	Post-graduate	50	39.4
Marital status	Single (never married)	22	17.3
	Married	66	52.0
	Partnered (not married)	20	15.7
	Single / separated / divorced	10	7.9
	Widowed	9	7.1
Living arrangements	Alone	25	19.8
	With partner / spouse / family	96	76.2
	Other	5	4.0
Location of residence	Town / city centre	27	21.4
	Suburbs	60	47.6
	Countryside	39	31.0
Employment status	Employed full time	43	33.9
	Employed part-time	15	11.8
	Self-employed	8	6.3
	Unemployed, looking for work	3	2.4
	Retired	35	27.6
	Unemployed, unable to work	3	2.3
	Student	10	7.9
	Household duties, carer, voluntary work	7	5.4
	Other	3	2.4

Table 5.2 Numbers of participants categorised by the International Classification of Disease Categories (ICD)

Illness classification	Number of participants	% of total chronic illness sample
Circulatory system	11	12.9
Endocrine, nutritional & metabolic	7	8.2
Respiratory system	16	18.8
Genitourinary	1	1.2
Dermatological	9	10.6
Nervous system	16	18.8
Musculoskeletal & connective tissue	18	21.2
Mental & behavioural	5	5.9
Digestive system	2	2.4
Chronic illness group <i>n</i>	85	

5.3.2 WHOQOL-BREF and EQ-5D VAS

A mixed model MANOVA was conducted with time as the within-subjects factor and health status and experimental condition as between-subjects factors. As shown in Table 5.3, analysis of the WHOQOL-BREF domain and EQ-5D VAS scores revealed a significant main effect of time ($F(5,113) = 2.42, p < .05, \eta^2 = 0.05$). Contrasts revealed that there was a significant contribution of the WHOQOL-BREF Psychological Health domain to the multivariate difference over time. Participants' psychological health scores had increased significantly between T1 and T2 and with a large effect size ($F(1,117) = 7.75, p < .05, \eta^2 = 0.62$) (See Table 5.4).

The MANOVA also revealed a significant between-subjects effect of health status (chronically ill or healthy) ($F(5,113) = 6.16, p < .001, \eta^2 = 0.21$) with a large effect size. Tests of between-subjects effects in the analysis showed that this difference related to participants' scores on the EQ-5D VAS and WHOQOL-BREF Physical Health Domain. Those participants who had a chronic illness had rated their health as significantly poorer on these measures than those who were healthy, and the effect size of the

difference was large (EQ-5D VAS: ($F(1,117) = 24.19, p < .001, \eta^2 = 0.17$, WHOQOL-BREF Physical Health domain: $F(1,117) = 22.98, p < .001, \eta^2 = 0.16$) (See Table 5.4).

Table 5.3 MANOVA analysis of WHOQOL-BREF domain and EQ-5D VAS scores, with time as the within subjects variable and health status and experimental condition as between subjects factors.

Variable:		<i>N</i>	T1 mean	T1 <i>SD</i>	T2 mean	T2 <i>SD</i>	
WHOQOL-BREF domains	Physical Health	Chronically ill	79	63.78	19.15	64.94	18.81
		Healthy	42	79.54	16.07	81.46	14.95
		Verbal guidance	55	70.54	18.41	72.62	17.00
		Written instructions	66	68.17	20.58	69.06	20.85
	Psychological Health	Chronically ill	79	63.44	15.27	65.61	15.99
		Healthy	42	67.64	11.95	70.08	11.20
		Verbal guidance	55	63.94	15.55	67.65	15.36
		Written instructions	66	65.69	13.23	66.76	14.08
	Social Relationships	Chronically ill	79	68.35	18.21	69.36	19.18
		Healthy	42	69.84	19.73	72.52	20.93
		Verbal guidance	55	66.82	20.25	69.85	21.25
		Written instructions	66	70.58	17.23	70.96	18.60
	Environment	Chronically ill	79	74.25	13.25	75.59	13.47
		Healthy	42	78.79	12.89	79.47	12.96
		Verbal guidance	55	75.57	13.14	78.06	12.08
		Written instructions	66	76.04	13.44	76.01	14.39
EQ-5D VAS	Chronically ill	79	68.80	17.40	69.14	17.22	
	Healthy	42	82.64	11.94	82.12	12.98	
	Verbal guidance	55	74.02	18.18	74.20	16.70	
	Written instructions	66	73.26	16.10	73.18	17.35	
MANOVA <i>df</i> = 5,113		<i>F</i>	<i>p</i>	η ²			
Within subjects effect of time		2.42	.040*	.052			
Between subjects' groups:							
Health status (chronically ill / healthy)		6.16	.001***	.214			
Experimental condition (verbal guidance / written instructions)		0.42	.836	.018			
Interactions:							
Time * health status		0.33	.896	.014			
Time * experimental condition		1.00	.421	.042			
Time * health status * experimental condition		0.36	.877	.016			
Health status * experimental condition		1.23	.298	.052			

* Significant at $p < .05$; *** Significant at $p < .001$

Table 5.4 Univariate results from a mixed factorial MANOVA analysis of WHOQOL-BREF domains and EQ-5D VAS, showing time as the within subjects variable and health status as a between subjects factor

Measure	Variable		<i>F</i>	<i>p</i>	η^2
Within subjects effect					
Time	WHOQOL-BREF	Physical Health	3.55	.062	.029
		Psychological Health	7.75	.006**	.062
		Social Relationships	3.13	.079	.026
		Environment	2.36	.128	.020
	EQ-5D	VAS	0.01	.938	.000
Between subjects effect					
Health status (chronically ill / healthy)	WHOQOL-BREF	Physical Health	22.98	.001***	.164
		Psychological Health	2.98	.087	.025
		Social Relationships	0.43	.513	.004
		Environment	3.20	.076	.027
	EQ-5D	VAS	24.19	.001***	.171

df = 1,117

** Significant at $p < .01$

*** Significant at $p < .001$

No effect of experimental condition (verbal guidance or written instructions) was found, indicating each mode of feedback was equally effective. There were no significant interactions between time, health status and experimental condition.

5.3.3 PANAS & GOSS-Q

Separate mixed factorial ANOVAs were used to examine the PANAS positive affect, PANAS negative affect and GOSS-Q scale scores over time.

As shown in Table 5.5, scores on the PANAS positive affect scale showed no significant difference between T1 and T2. Neither were found any effects of health status or experimental condition, nor were any interactions present. The same was true of the PANAS negative affect scale (Table 5.6).

Table 5.5 Mixed factorial ANOVA analysis of PANAS positive affect showing time as the within subjects variable and health status and experimental condition as between subjects factors

Measure	Between subjects' group	N	T1 mean	T1 SD	T2 mean	T2 SD
PANAS positive affect	Chronically ill	85	30.36	8.13	30.65	8.59
	Healthy	43	31.77	7.35	31.30	6.77
	Verbal guidance	58	30.11	8.44	31.11	8.30
	Written instructions	70	31.44	7.37	30.67	7.80
df = 1,124			F	p	η²	
Within subjects effect of time			0.01	.924	.000	
Between subjects' groups:						
Health status (chronically ill / healthy)			0.69	.407	.006	
Experimental condition (verbal guidance / written instructions)			0.00	.980	.000	
Interactions						
Time * health status			0.62	.433	.005	
Time * experimental condition			0.90	.345	.007	
Time * health status * experimental condition			2.67	.105	.021	
Health status * experimental condition			0.74	.392	.006	

Table 5.6 Mixed factorial ANOVA analysis of PANAS negative affect^a showing time as the within subjects variable and health status and experimental condition as between subjects factors

Measure	Between subjects' group	N	T1 mean	T1 SD	T2 mean	T2 SD
PANAS negative affect	Chronically ill	85	14.21	5.27	13.94	5.86
	Healthy	43	12.65	3.99	12.86	4.41
	Verbal guidance	58	13.43	4.65	13.53	4.95
	Written instructions	70	13.90	5.15	13.61	5.83
df = 1,124			F	p	η²	
Within subjects effect of time			0.32	.574	.003	
Between subjects' groups:						
Health status (chronically ill / healthy)			2.25	.136	.018	
Experimental condition (verbal guidance / written instructions)			0.19	.662	.002	
Interactions						
Time * health status			1.89	.171	.015	
Time * experimental condition			1.66	.200	.013	
Time * health status * experimental condition			1.08	.300	.009	
Health status * experimental condition			0.48	.490	.004	

^a after reciprocal transformation applied

As can be seen in Table 5.7, scores on the GOSS-Q scale were not found to have changed significantly over time. However the analysis did reveal a significant between-subjects effect of health status, with a medium effect size ($F(1,125) = 15.18, p < .001, \eta^2 = 0.11$). QoL-related goal orientation scores were shown to be significantly lower for those who had a chronic illness (T1 M = 24.99, SD = 4.85, T2 M = 25.21, 4.49) than those who were healthy (T1 M = 28.05, SD = 5.14, T2 M = 28.52, SD = 5.11). Although all mean scores were above the midpoint of the scale (24), indicating that all participants reported overall movement towards rather than away from their ideal QoL, the higher scores of healthy participants suggested that participants in this group had reported more rapid movement in this positive direction. There were no significant interactions between time, health status and condition.

Table 5.7 Mixed factorial ANOVA analysis of GOSS-Q showing time as the within subjects variable and health status and experimental condition as between subjects factors

Measure	Between subjects' group	N	T1 mean	T1 SD	T2 mean	T2 SD
GOSS-Q	Chronically ill	85	24.99	4.85	25.21	4.49
	Healthy	44	28.05	5.14	28.52	5.11
	Verbal guidance	58	26.32	5.54	27.02	5.46
	Written instructions	71	25.79	4.82	25.78	4.44
df = 1,125			F	p	η^2	
Within subjects effect of time			1.41	.237	.011	
Between subjects' groups:						
Health status (chronically ill / healthy)			15.18	.001***	.108	
Experimental condition (verbal guidance / written instructions)			1.88	.172	.015	
Interactions						
Time * health status			0.18	.669	.001	
Time * experimental condition			1.22	.272	.010	
Time * health status * experimental condition			0.00	.981	.000	
Health status * experimental condition			0.53	.469	.004	

*** Significant at $p < .001$

Table 5.8 MANOVA analysis of WHOQOL-Importance domain scores, with time as the within subjects variable and health status and experimental conditions as between subjects factors

Variable:			<i>N</i>	T1 mean	T1 <i>SD</i>	T2 mean	T2 <i>SD</i>
WHOQOL-Importance	Physical Health	Chronically ill	82	77.41	10.14	78.15	10.06
		Healthy	44	84.50	12.44	84.94	12.78
		Verbal guidance	57	79.25	12.42	80.45	11.82
		Written instructions	69	80.41	10.67	80.58	11.32
	Psychological Health	Chronically ill	82	75.06	11.45	75.34	12.53
		Healthy	44	78.77	14.10	81.53	11.76
		Verbal guidance	57	75.46	13.67	75.85	13.22
		Written instructions	69	77.09	11.52	78.86	11.94
	Social Relationships	Chronically ill	82	68.90	15.10	69.04	15.56
		Healthy	44	73.58	18.24	73.86	17.75
		Verbal guidance	57	69.69	15.87	70.10	15.85
		Written instructions	69	71.32	16.81	71.24	17.04
	Environment	Chronically ill	82	79.20	11.13	79.23	10.13
		Healthy	44	79.98	13.31	81.65	12.17
		Verbal guidance	57	78.90	12.88	80.43	11.31
		Written instructions	69	79.94	11.08	79.78	10.62
MANOVA <i>df</i> = 4,119			<i>F</i>	<i>p</i>	η^2		
Within subjects effect of time			0.82	.516	.027		
Between subjects' groups:							
Health status (chronically ill / healthy)			3.91	.005**	.116		
Experimental condition (verbal guidance / written instructions)			0.45	.774	.015		
Interactions:							
Time * health status			0.68	.605	.022		
Time * experimental condition			0.85	.497	.028		
Time * health status * experimental condition			1.13	.347	.037		
Health status * experimental condition			0.29	.882	.010		

** Significant at $p < .01$

5.3.4 WHOQOL-Importance

Scores on the WHOQOL-Importance domains were not found to have changed significantly over time. However, the MANOVA analysis again revealed a significant between-subjects effect of health status with a medium effect size ($F(4,119) = 3.91, p < .01, \eta^2 = 0.12$) (See Table 5.8). As shown in Table 5.9, from this analysis the univariate tests of between-subjects effects showed that participants' scores on the Importance of Physical Health and Importance of Psychological Health domains had contributed to the multivariate between-groups difference, with large effect sizes (WHOQOL Importance Physical Health: $F(1,122) = 12.39, p < .001, \eta^2 = 0.92$, WHOQOL Importance Psychological Health domain: $F(1,122) = 5.42, p < .05, \eta^2 = 0.43$). The data therefore showed that those who had a chronic illness had rated physical health and psychological health as significantly less important than those who were healthy.

Table 5.9 Univariate results from mixed factorial MANOVA analysis of WHOQOL-Importance domains showing health status as a between subjects factor

Measure	Variable		<i>F</i>	<i>p</i>	η^2
Between subjects effect					
Health status (chronically ill / healthy)	WHOQOL- Importance	Physical Health	12.39	.001***	.092
		Psychological Health	5.42	.022*	.043
		Social Relationships	2.71	.102	.022
		Environment	0.79	.376	.006

$df = 1,122$

* Significant at $p < .05$

*** Significant at $p < .001$

The findings from this series of analyses supported the hypothesis that receiving feedback on subjective QoL and importance judgements would bring about positive effects, although only in terms of increased psychological health scores as measured by the WHOQOL-BREF.

These analyses did not support the prediction that receiving verbal guidance to review feedback on subjective QoL and importance judgements would have a greater impact on QoL than reviewing feedback according to written instructions, instead indicating that both feedback methods worked equally.

5.3.5 Regression analyses of variables contributing to psychological health change over time

Having found a significant increase in the WHOQOL-BREF Psychological Health domain scores over time (section 5.3.2), multiple regression analyses were conducted to assess the percentage of variance in change over time that could be explained by other variables. Dichotomised categorical demographic variables relating to age (18-44, 45+), gender, and whether or not participants had a chronic illness were firstly entered into the analysis as predictor variables. The overall regression was non-significant with a small effect size (Multiple $R = .11$, adjusted $r^2 = -.01$, $p = .69$). Neither was any individual variable found to be significantly related to the change in Psychological Health over time. This result suggested that age, gender or illness did not explain the variation in changes in Psychological Health over time.

In a second analysis, independent variables were the baseline (T1) scores from the PANAS, GOSS-Q, and EQ-5D VAS. Again the overall model was not significant and small (Multiple $R = .24$, adjusted $r^2 = -.03$, $p = .11$) suggesting that these variables together did not explain change in Psychological Health over time. Additionally, values of the regression coefficients showed that none made a significant individual contribution to change in Psychological Health over time.

Taken together these results showed that the change detected in scores on the WHOQOL-BREF Psychological Health domain over time could not be predicted by age, gender or presence of chronic illness, or by baseline scores on other QoL, mood or QoL-related goal orientation measures.

5.3.6 Exploratory analysis of the differences between quality of life and importance

As discussed in section 5.2.4 of this chapter, the feedback methodology asked participants to consider the gaps between their WHOQOL-BREF core scores and their associated WHOQOL Importance scores. As discussed earlier in section 5.2.7, it could not be assumed that each was measured on the same metric. Nevertheless exploratory analyses of the gaps between core and importance were undertaken for scores at T1 and at T2 and the data were also examined to find out if the magnitude of these gaps changed between T1 and T2.

Exploratory dependent *t* tests on the whole sample found that Importance was rated significantly higher than QoL at both time points for the physical health domain (T1 $t(125) = -5.94, p < .001$, T2 $t(124) = -5.54, p < .001$); the psychological health domain (T1 $t(128) = -6.54, p < .001$, T2 $t(127) = -6.54, p < .001$) and the environment domain (T1 $t(128) = -2.44, p < .05$, T2 $t(127) = -2.41, p < .05$), but not the social domain (see Table 5.10).

Table 5.10 Dependent *t* tests showing differences between WHQOL-BREF domain scores and their associated WHOQOL Importance domains at T1 and T2

						Dependent <i>t</i> tests (<i>df</i> = 124-128)		
Domain	<i>N</i>	WHOQOL- BREF mean	WHOQOL- BREF <i>SD</i>	Importance mean	Importance <i>SD</i>	Mean diff.	<i>t</i>	<i>P</i>
T1								
Physical	126	69.28	19.54	79.94	11.47	-10.66	-5.94	.001***
Psychological	129	65.04	14.56	76.36	12.47	-11.32	-6.54	.001***
Social	129	69.32	18.60	70.25	16.49	-0.94	-0.47	.638
Environment	129	75.68	13.35	79.28	11.91	-3.60	-2.44	.016*
T2								
Physical	125	70.68	19.20	80.55	11.53	-9.87	-5.54	.001***
Psychological	128	67.07	14.74	77.40	12.60	-10.33	-6.54	.001***
Social	129	70.80	19.60	71.02	16.50	-0.22	-0.11	.915
Environment	128	76.66	13.51	79.92	10.92	-3.26	-2.41	.017*

* Significant at $p < .05$

*** Significant at $p < .001$

5.3.6.1 Analyses of differences by health status

When this analysis was repeated for just the chronically ill group, the results were similar to those of the whole sample (see Table 5.11). The gap between QoL and Importance was again significant for the physical health and psychological health domains at both time points ($p < .001$) with importance being rated more highly. It was also significant for the environment domain at T1 ($p < .01$) and at T2 ($p < .05$). No significant differences were found between QoL and Importance at either time point for

Table 5.11 Dependent samples *t* tests showing differences by health status between WHOQOL-BREF and associated WHOQOL Importance domains at T1 and T2

<i>df</i> = 43-84																
Chronically ill									Healthy							
Domain	<i>N</i>	WHOQOL-BREF mean	WHOQOL-BREF <i>SD</i>	Importance mean	Importance <i>SD</i>	Mean diff.	<i>t</i>	<i>p</i>	<i>N</i>	WHOQOL-BREF mean	WHOQOL-BREF <i>SD</i>	Importance mean	Importance <i>SD</i>	Mean diff.	<i>t</i>	<i>p</i>
T1																
Physical	82	64.06	19.10	77.50	10.18	-13.44	-5.84	.001***	44	79.00	16.54	84.50	12.44	-5.49	-2.03	.049*
Psychological	85	63.86	15.49	75.11	11.43	-11.25	-5.46	.001***	44	67.31	12.44	78.77	14.10	-11.45	-3.60	.001***
Social	85	68.73	18.03	68.53	15.34	0.20	0.08	.933	44	70.45	19.81	73.58	18.24	-3.12	-0.85	.401
Environment	85	74.30	13.30	78.91	11.19	-4.61	-2.67	.009**	44	78.34	13.20	79.98	13.31	-1.64	-0.59	.555
T2																
Physical	81	64.93	18.65	78.16	10.10	-13.23	-5.77	.001***	44	81.25	15.46	84.94	12.78	-3.69	-1.44	.158
Psychological	84	65.53	15.97	75.23	12.55	-9.70	-4.64	.001***	44	70.02	11.67	81.53	11.76	-11.52	-5.02	.001***
Social	85	69.56	18.92	69.55	15.72	0.01	0.00	.996	44	73.20	20.85	73.86	17.75	-0.66	-0.18	.857
Environment	84	75.30	13.38	79.02	10.17	-3.72	-2.22	.029*	44	79.27	13.54	81.65	12.17	-2.37	-1.02	.311

* Significant at $p < .05$; ** Significant at $p < .01$; *** Significant at $p < .001$

the social domain indicating a greater correspondence between core QoL and importance for this domain only.

Table 5.11 also shows that when the scores of the healthy group were analysed independently, importance was significantly higher than core QoL for the physical health and psychological health domains at T1 (physical health $t(43) = -2.03, p < .05$; psychological health $t(43) = -3.60, p < .01$) and for the psychological domain alone at T2 ($t(43) = -5.02, p < .001$). This indicated the gap between core physical health and its importance was no longer significant at T2 for those in the healthy group. Changes in the magnitude of gaps will be discussed in section 5.3.6.3.

These results indicated that Importance was higher than core QoL in more domains for those who were chronically ill than for those who were healthy (although core QoL was lower than Importance for both groups in relation to psychological health). This suggested less difference between actual QoL and Importance for healthy participants.

5.3.6.2 *Analyses of differences by experimental condition*

As shown in Table 5.12, Importance was significantly higher ($p < .001$) than core QoL at both time points for the physical health domain for both experimental conditions (verbal guidance: T1 $t(55) = -3.49, p < .001$, T2 $t(56) = -3.68, p < .001$; written instructions: T1 $t(69) = -4.81, p < .001$, T2 $t(67) = -4.18, p < .001$). The same was found for the psychological health domain (verbal guidance: T1 $t(57) = -3.81, p < .001$, T2 $t(57) = -3.45, p < .001$; written instructions: T1 $t(70) = -5.61, p < .001$, T2 $t(69) = -5.76, p < .001$). The only difference between conditions was that Importance was significantly higher for the environment domain for the written instructions group at T2 ($t(69) = -2.03, p < .05$) but this was not true for the verbal guidance group. These results suggested little differential effect on Importance between the two experimental conditions.

5.3.6.3 *Analyses of differences in the magnitude of gaps between T1 and T2*

Exploratory analyses of the magnitude of gaps between QoL and Importance over time was also conducted. No significant differences were found between the magnitude of the

Table 5.12 Dependent samples *t* tests showing differences by experimental condition between WHQOL-BREF and associated WHOQOL Importance domains at T1 and T2

<i>df</i> = 55-70																
Verbal guidance									Written instructions							
Domain	<i>N</i>	WHOQOL-BREF mean	WHOQOL-BREF <i>SD</i>	Importance mean	Importance <i>SD</i>	Mean diff.	<i>t</i>	<i>p</i>	<i>N</i>	WHOQOL-BREF mean	WHOQOL-BREF <i>SD</i>	Importance mean	Importance <i>SD</i>	Mean diff.	<i>t</i>	<i>p</i>
T1																
Physical	56	70.17	18.45	79.26	12.54	-9.09	-3.49	.001***	70	68.56	20.47	80.48	10.61	-11.92	-4.81	.001***
Psychological	58	64.01	15.97	75.31	13.59	-11.30	-3.81	.001***	71	65.88	13.36	77.21	11.51	-11.33	-5.61	.001***
Social	58	67.10	20.32	69.54	15.73	-2.44	-0.84	.402	71	71.13	17.00	70.83	17.18	0.29	0.11	.915
Environment	58	75.70	13.05	78.89	12.77	-3.19	-1.48	.146	71	75.66	13.68	79.60	11.25	-3.94	-1.93	.057
T2																
Physical	57	72.34	16.88	80.60	11.80	-8.26	-3.68	.001***	68	69.28	20.97	80.51	11.39	-11.22	-4.18	.001***
Psychological	58	67.67	15.56	75.98	13.14	-8.30	-3.45	.001***	70	66.57	14.13	78.57	12.11	-12.00	-5.76	.001***
Social	58	69.97	21.23	70.04	15.72	-0.07	-0.02	.982	71	71.48	18.28	71.82	17.19	-0.34	-0.12	.901
Environment	58	77.90	12.01	80.39	11.21	-2.49	-1.31	.196	70	75.64	14.65	79.53	10.74	-3.90	-2.03	.046*

* Significant at $p < .05$; *** Significant at $p < .001$

gaps at T1 and T2 for any WHOQOL domain for the whole sample or for the chronically ill or healthy groups. When analysed by experimental condition the magnitude of gap for the verbal guidance condition decreased significantly between T1 and T2, but only for the psychological domain (T1 $M = 28.02$, $SD = 17.19$, T2 $M = 22.01$, $SD = 15.31$, $t(26) = 2.33$, $p < .05$). This indicated that the gaps between QoL and Importance remained stable over time and were affected very little by receipt of the feedback intervention.

5.3.7 Post-study evaluation of change questionnaire (T3)

5.3.7.1 Quantitative data relating to self-perceived change

Of the 129 participants, the substantial majority (84%) reported in the T3 questionnaire that their QoL had remained “about the same” after taking part in the study. A small proportion (2%) felt their QoL to be worse, and 14%, that it had improved.

As illustrated in Figure 5.4, of those who responded, 65% stated that the way they thought about their QoL had changed and 34% perceived their goals or expectations had subsequently altered. Fewer than 9% of respondents said that aspects of their physical health, or environment had been affected as a result of taking part in the study. 12% of respondents felt their social relationships had changed. However 40% reported that they felt their psychological health had changed. One sample binomial tests of the proportions reporting “change” or “no change” confirmed that these results were significant for all perceived change variables ($p < .05$), with medium to large effect sizes (0.20 – 0.85) (see Table 5.13).

A Chi-square analysis of reported change found no association between the reporting of change and whether or not participants had a chronic illness. Full details are given in Table 5.14.

Figure 5.4 Percentages of respondents reporting change or no change

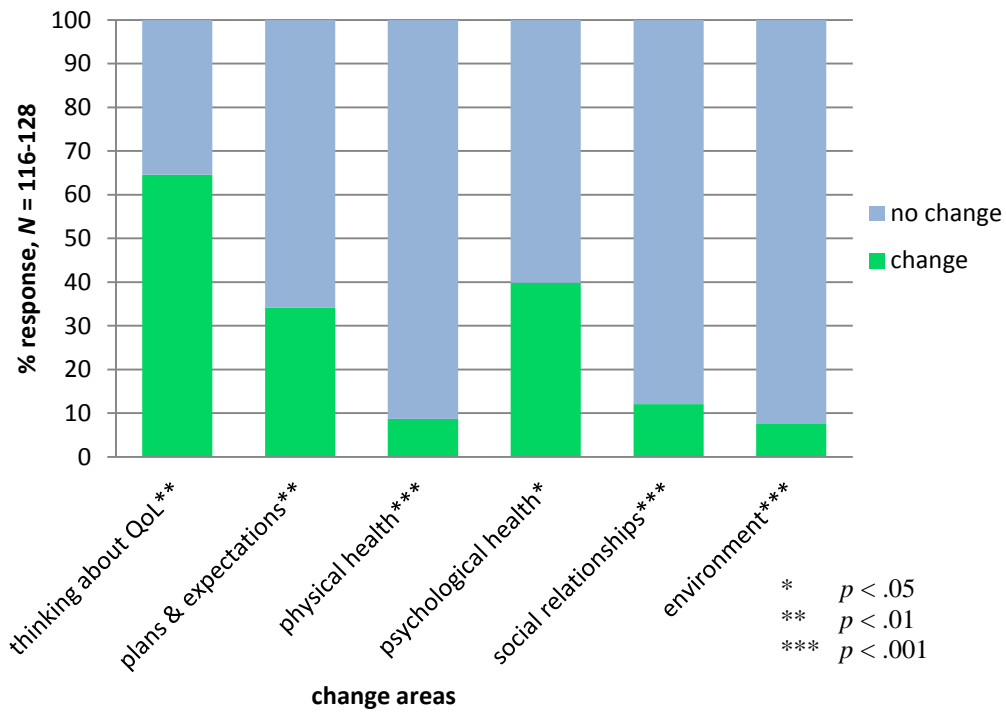


Table 5.13 Percentages of respondents reporting change or no change

Change / no change %	Thinking about QoL N=127	Plans & expectations N=126	Physical health N=127	Psychological health N=128	Social relationships N=116	Environment N=117
Change	64.5	34.2	8.6	39.8	12.3	7.8
No change	35.4	65.9	91.3	60.2	87.9	92.3
<i>Binomial p (2-tailed)</i>	.001***	.001***	.001***	.027*	.001***	.001***
<i>Cohen's g</i>	.291 ^a	.314 ^b	.827 ^b	.204 ^a	.756 ^b	.845 ^b

* $p < .05$, *** $p < .001$

^a medium effect size, ^b large effect size

Table 5.14 Percentages of respondents reporting change or no change, by health status

Health status	Thinking about QoL	Plans & expectations	Physical health	Psycho-logical health	Social relationships	Environment
Chronically ill:						
% Change	67.9	33.7	10.7	41.2	12.2	8.0
% No change	32.1	66.3	89.3	58.8	87.8	92.0
(N)	(84)	(83)	(84)	(85)	(74)	(75)
Healthy						
% Change	58.1	34.9	4.7	37.2	11.9	7.1
% No change	41.9	65.1	95.3	62.8	88.1	92.9
(N)	(43)	(43)	(43)	(43)	(42)	(42)
χ^2	1.17	.02	1.32	.187	.002	.028
P^a	.279	.897	.331 [†]	.665	.967	1.00 [†]

^aasymptotic, 2-sided[†] exact p value, due to low expected frequencies

5.3.7.2 Qualitative data relating to change

Of the 129 participants who completed the T3 questionnaire, 67 (52%) made comments in addition to responding to the scale questions. Although the questions guided participants' reflections, several recurring themes were identified consistently across the data and were coded accordingly.

Table 5.15 shows the frequency of comments made in each coding category. Over half of participants commenting (57%) made reference to changes in their thoughts or perceptions about their lives, as a result of taking part in the study. Slightly fewer (48%) mentioned changes they had made, or wanted to make, in relation to their thinking processes, or to material aspects of their lives. A small proportion (15%) reported that taking part had confirmed to them their existing beliefs about their QoL. For a small number of participants (9%), comments revealed thinking about QoL to be a "novel" activity and/or that it had served to reveal to them where their aspirations differed from the actuality of their lives (13%). Full transcripts of the comments within the coding framework are given in Appendix Y. However, illustrative comments are given below. In summary, the majority of participants who responded at T3 reported that taking part

in the study had brought about an effect in terms of changing their thoughts or perceptions about their QoL. This was consistent with the quantitative findings from the T1 and T2 analyses.

Table 5.15 Frequency of comments in the T3 questionnaire

Code	Participants commenting (<i>N</i> =67) <i>n</i> (%)		Total number of comments
Effect on perceptions			
Change in thoughts or perceptions	38	(57)	51
Identification of differences	9	(13)	9
Acknowledgement of lack of prior thought about QoL	6	(9)	6
Confirmation of existing beliefs or thoughts	10	(15)	11
Intentions to change attitudes / behaviours	32	(48)	46
Effect on affect			
Increased negative feelings	6	(9)	6
Increased positive feelings	18	(27)	27

a) Changes in thoughts or perceptions

Comments revealed a recurring theme relating to changes in the ways participants thought about their QoL overall, or aspects of it. Typically comments referred to having a better understanding, or a different view, about what was important:

“[I] have a better understanding of what I need to obtain a better quality of life.” (female, age group 18-24)

“I have a different view of what is important to me” (male, age group 55-64)

“Seeing the areas in black and white and how important they are to me personally has made me look at those aspects of my own quality of life in a different way”(female, age group 35-44)

“It drew my attention to some aspects of my health that are important but I had failed to recognize their importance until now.” (female, age group 55-64)

It was also evident that thinking about QoL was not an activity customarily undertaken. Comments revealed a sense of novelty of thinking about one's life in this way and in considering its various facets:

"I don't normally think about my quality of life. Perhaps I will now." (female, age group 65-74)

"I will pay more attention to other parts which I have never thought of it as part of quality of life" (male, age group 25-34)

"I don't think I had really thought about my quality of life previously..." (female, age group 18-24)

Similarly revealing were comments relating to how participation in the study had promoted cognitive reflection. These suggested that the study had provided participants with an opportunity to question or contemplate their QoL:

"[It] made me stop & think." (female, age group 55-64)

"I now consider things in more depth." (female, age group 65-74)

"...it has made me think about all the different aspects that can affect your life and how they are connected" (female, age group 25-34)

"It has made me question and reflect upon certain areas of my life..." (female, age group 25-34)

Within the comments was the suggestion that taking part in the study could be self-affirming. For some, the comments reflected an implicit sense of appreciation when feedback was consistent with self-perception:

"A helpful and thought-provoking analysis, but mainly reassuring..." (male, age group 35-44)

"It's good to see where I am scoring well, as well as the areas where I already knew I was scoring badly." (female, age group 18-24)

“Has confirmed a lot of what I thought about myself in various aspects.” (male, age group 65-74)

“It is interesting, and lucky for me, to see that the areas of my life are roughly in line with the importance I give them.” (female, age group 55-64)

b) Intentions to make changes

Another commonly recurring theme was the motivation to make changes, either in terms of behaviours, attitudes or beliefs, as a result of taking part in the study. Participants frequently expressed their greater awareness of their QoL and their subsequent general intentions to make changes in order to improve their wellbeing:

“[The study] has underlined some areas that I was aware of but can now concentrate on doing something about them” (female, age group 45-54)

“I will be taking more time to look at where the problems lie in my life and how I can go about changing them to make me feel better” (female, age group 18-24)

“I will try to be more aware of the positives and take action, where possible, to address the negatives” (female, age group 55-64)

“... helps me to identify and isolate areas in need of improvement. This is great because rather than having the insurmountable task of 'trying to make my life better', I can work on specific areas with specific actions.” (male, age group 25-34)

Other participants were more specific in terms of the changes they would be seeking to make. In these cases there was a sense of focusing in on those specific aspects that primarily affected their QoL. For example:

“I realise that there are many things I could do to improve my quality of life, and that these are primarily related to emotional/psychological health” (female, age group 18-24)

“I want to work towards the social environment and social relationships that I want to be at” (female, age group 18-24)

“I have realised that my work environment is not as good for me as before therefore I need to take steps to change it and move on.” (female, age group 25-34)

“[I should] perhaps focus on working towards improved feelings about myself in terms of negative thoughts.” (female, age group 25-34)

c) Negative effects

As would reasonably be expected, not all comments were resoundingly positive. Six participants reported increased negative feelings as a result of taking part and two, a reduction in positive mood:

“[I] possibly feel a bit worse from seeing the gaps on the charts” (female, age group 25-34)

“[I] feel frustrated with certain situations” (female, age group 45-54)

“[The feedback] ...made me think, slightly depressive” (male, age group 25-34)

However, even though the feedback may have brought about increased concern, two comments nevertheless suggested that it had done so through identifying and focusing on specific issues, rather than causing generalised anxiety,

“I have realised I do get depressed” (female, age group 75+)

“[I am now] more concerned about health & finances” (male, age group 75+)

One participant's comments also highlighted how their negative feelings stemmed from a realisation of lack of control:

“ ... I've come to believe that the things which bring my quality of life down are largely beyond my control which is frustrating, scary and can lead me to feel angry and bitter (so I try not to think about it)” (male, age group 75+)

d) Positive implications of the study on self-perceived affect

Reassuringly, more than one quarter of participants reported a positive effect on mood as a result of the study. Many of these comments reflected a sense of gratitude for positive

QoL and an appreciation of those aspects that contributed to their overall sense of wellbeing:

“I am grateful for my “positive” thinking” (male, age group 75+)

“[Taking part in the study has] made me see I am generally quite positive about life and lucky to have many aspects of quality of life” (female, age group 25-34)

“I think from doing this study it has made me realise how lucky I am that my quality of life is so good and that I don’t really have any issues in relation to it” (female, age group 25-34)

Notably, the data suggested that this realisation had also brought about an improved level of positive affect and a higher sense of self-efficacy for some participants:

“I now feel positive... and don't feel so overwhelmed.” (female, age group 35-44)

“I've focused on the fact that my quality of life could be significantly worse which makes me feel more positive” (female, age group 25-34)

“My outlook on my current lifestyle is much more positive” (female, age group 18-24)

5.3.7.3 Quantitative data relating to helpfulness

As shown in Table 5.16, 50% of respondents expressed their belief that taking part would prove to be helpful in the short term (i.e. two weeks after taking part). This proportion increased to 56% who felt it would be helpful in the medium term (i.e. within 3 months of taking part), and 54% stated they believed it would be helpful to them in the long term (i.e. more than 3 months). Fewer than 10% of participants felt that taking part had been unhelpful to them. When analysed using chi-square, differences between observed and expected frequencies were significant for all time points ($p < .001$) with large effect sizes (Cohen’s $w \geq .5$).

Table 5.16 Percentages of responses to the question “How helpful will your experience of this study be to you in the future?”

		% of participants					
How helpful will your experience of this study be to you in the future?		In the next 2 weeks? (N=127)		In the next 3 months? (N=122)		Longer than 3 months? (N=124)	
Very unhelpful	Unhelpful	2.4	9.5	2.5	8.2	2.4	7.2
Mostly unhelpful		1.6		1.6		1.6	
Somewhat unhelpful		5.5		4.1		3.2	
Neither helpful nor unhelpful		40.9	40.9	36.1	36.1	37.9	37.9
Somewhat helpful	Helpful	37.8	49.6	44.3	55.8	36.3	54.8
Mostly helpful		9.4		10.7		13.7	
Very helpful		2.4		0.8		4.8	
χ^2			34.31		41.77		43.27
<i>p</i> (asymptotic)			.001***		.001***		.001***
Cohen's <i>w</i> ($\sqrt{\chi^2 / N}$)			.52		.59		.59
Chronically ill %							
Unhelpful			6.0		7.7		6.3
Neither helpful nor unhelpful			39.8		33.3		35.0
Helpful			54.2		59.0		58.8
Healthy %							
Unhelpful			15.9		9.1		9.1
Neither helpful nor unhelpful			43.2		40.9		43.2
Helpful			40.8		50.0		47.7
χ^2			4.08		.921		1.45
Exact <i>p</i> (2 sided) ^a			.14		.68		.51

^a Exact *p* used as some cells had expected counts < 5

*** *p* < .001

Analysis of helpfulness, according to whether participants had a chronic illness or were healthy was also conducted and results are also given in Table 5.16. Results revealed that a higher proportion of those who had a chronic illness reported that they would find

their experience of the study to be helpful in the short, medium and long terms compared to healthy participants. However, applying a chi-square analysis to each set of figures, there was no association found between reporting of helpfulness and health status.

5.4 Discussion

The main aim of this study was to explore whether receiving feedback on subjective judgements might lead to changes in consideration of QoL, QoL-related goal orientation and mood. It also set out to examine whether the pattern of changes differed when the feedback intervention took a one-to-one verbal guidance format or when individuals received written instructions on how to read and interpret their feedback.

5.4.1 Effects over time

It had been hypothesised that the strategic use of QoL feedback, as the basis of a SRT grounded intervention, would have a positive effect on individual's later judgements about their QoL, on their emotional state, and on their QoL-related goal orientation. The study demonstrated that providing individualised feedback on subjective judgements of QoL was associated with improved ratings of QoL in terms of WHOQOL-BREF psychological health domain scores. However no effects were found for the physical, social relationships or environment aspects of core QoL as measured by the WHOQOL-BREF. Neither were significant effects found in terms of subjective judgements of overall health status, mood, QoL-related goal orientation, or the importance of QoL.

Despite the limited effects, the finding nevertheless indicated support for the sensitivity of the WHOQOL-BREF instrument to detect change in QoL over time in the psychological health of a community sample. In the Psychological Health domain the increase in ratings of QoL showed a medium effect size, supporting the hypothesis, that sharing QoL information with individuals has potential to bring about improved QoL, and specifically psychological QoL. This is consistent with the findings of Velikova et al.(2004) and Del Wit et al. (2008) that emotional wellbeing and mental health improved after feedback of QoL information.

Although a medium effect size was found for psychological health scores over time in the present study, minimum clinically important differences, against which to interpret this finding, have yet to be established for the domains of the WHOQOL-BREF. Nevertheless the test-retest reliability of the WHOQOL-BREF has been established to be good (as discussed in Chapter 3), evidencing its reliability over time. This was confirmed in a recent large study (n = 4628) of both ill and well people across the UK (Skevington & McCrate, 2012) which found strong positive correlations between domain scores at two time points and no significant differences in scores over time. The suggestion is therefore, that the increase in psychological health scores found in the present study was indicative of change that would not have been otherwise expected from repeated measurement of QoL using the WHOQOL-BREF.

Furthermore Skevington and McCrate (2012) have also investigated the responsiveness of the WHOQOL-BREF by examining the effects of different interventions for a subgroup of the overall sample. Though significant results were scarce, they anticipated and confirmed small to medium effects in psychological health domain scores resulting from established interventions for depression and chronic fatigue. This suggests that the change in psychological health found in the present study was also plausible in relation to what is already known about the test-retest reliability of the WHOQOL-BREF.

As mentioned above, improvements over time were not found for the WHOQOL-BREF physical health domain scores. Whilst an improvement in physical QoL had been previously demonstrated in Velikova's et al. (2004) study, this had resulted from the completion of the study measures (a disease-specific QoL questionnaire and an anxiety and depression scale), not specifically from feedback of the QoL information generated. (Velikova had found no differences between the intervention group (questionnaire completion with feedback) and attention-control group (questionnaire completion without feedback), but had found the physical wellbeing scores of both these groups were different from those of the control group (no questionnaire completion), therefore suggesting the effect lay with instrument completion). Furthermore, the study by De Wit et al. (2008) had also found no effect on physical QoL from discussing QoL with patients. These results are unsurprising, given that QoL feedback or discussion of QoL issues is unlikely to make major changes in physical QoL.

That changes in scores over time were not found for measures except the WHOQOL-BREF was not entirely surprising. Previous studies investigating the effects of QoL assessments using the Functional Assessment of Cancer Therapy (FACT), the Palliative Care Quality of Life Index (PQLI) and the Functional Living Index (FLIC) as outcome measures, have similarly found no effects (Hilarius et al., 2008; Mills et al., 2009; Rosenbloom et al., 2007). It may be the case that the other measures employed in the present study were not sufficiently sensitive to detect the changes taking place. Concerns about the responsiveness of the EQ-5D were discussed earlier in Chapter 4. Indeed, as was mentioned in the introduction to this chapter, the previous study by Santana et al. (2010) concluded that their finding of no effect of QoL feedback may have stemmed, at least in part, from the lack of responsiveness of the EQ-5D measure they used. As discussed in the previous chapter, the GOSS-Q was adapted for this study and has only been cited in two other studies in its original version. Its sensitivity to change had not been tested prior to its application in this research and the use of this measure was therefore exploratory. It is also plausible that the use of generic measures may have had a bearing on the results. It has been asserted that disease specific measures may be more responsive to change than generic ones (Santana et al., 2010). However, while using disease specific measures might provide more conclusive evidence in future research, this approach cannot be applied in studies, such as the present study, where multiple and heterogeneous disease types are included.

No changes were detected over time by the PANAS. This was surprising as the PANAS is an established instrument with proven psychometric properties (see Chapter 4), although it has not been examined longitudinally in relation to the effects of feedback. The PANAS was used in a recent study by Gunson (2011) into the longitudinal effects of positive life events. She found a reduction in negative affect was associated with positive life events, although no corresponding increase in positive affect was evident. Gunson concluded experiencing positive events may buffer against negative affect, therefore explaining the reduction found. However, no similar effect was found in the present study in terms of the feedback intervention. This may be because both good *and* poor QoL were illustrated in the graphical summary profiles. Future investigations of the PANAS, alongside the WHOQOL-BREF, would be helpful in examining the respective sensitivity of the measures to detect changes instigated by psychological interventions.

In considering the limited effect found, it is also possible that this was limited to within the WHOQOL-BREF because it was this instrument that generated the basis of the feedback that participants received. However this was not true of the WHOQOL Importance scores, which were also contained in the feedback, as these demonstrated no improvement over time in the main effects analysis. Nevertheless the latter finding was not unanticipated as the WHOQOL Importance specifies no time frame (indeed, unlike the WHOQOL-BREF where respondents are asked to rate their QoL over the previous two weeks, the instructions to the importance questionnaire specifically point out that responses should *not* relate solely to the prior two weeks). Because of this it might be considered a more stable construct and therefore was not expected to change in the short term. Other findings related to the analysis of the WHOQOL Importance in relation to WHOQOL-BREF scores are discussed in more detail in section 5.4.4.

Interestingly results of the regression analysis showed that age, gender and chronic illness were not predictors of change in WHOQOL-BREF Psychological Health domain scores over time. This was also true of baseline scores from the other instruments used as measures in the study (EQ-5D VAS, PANAS and GOSS-Q). While there may be associations between these measures in relation to scores at specific time points (see Chapter 6 for further analysis of correlations between instruments), that they were not predictors of change in the present study suggests that the difference between psychological health T1 and T2 scores was related to other factors. As only a handful of studies have investigated improvements in QoL post feedback, and fewer still have found positive effects, little evidence exists regarding factors that might be predictive of QoL change. However, in line with the present study, De Wit et al. (2008) similarly found that positive effects from QoL feedback for patients with diabetes were *not* associated with health status (as measured by levels of glycaemic control). It would be interesting in future studies to investigate other factors that might explain changes in psychological health after QoL feedback. For example, in Chapter 2, the concept of perceived self-efficacy was introduced and it is possible that this may have a role to play in predicting change over time.

5.4.2 *Verbal guidance versus written instructions*

It had also been predicted that receiving verbal guidance to review feedback on subjective QoL and importance judgements would have a greater impact on QoL than receiving written instructions for reviewing feedback. This hypothesis had been based on prior evidence that patients want to discuss their QoL (Detmar et al., 2000). However, the analyses found no differences between the scores of participants in each of these groups.

This result has implications for any critique of the methodologies employed. Firstly, it suggests that the written instructions and the verbal scripts employed in the studies were reflective of one another, as neither showed a superior effect on subsequent wellbeing. From a pragmatic perspective, this conclusion has implications for future implementation of this approach as it would suggest that either method is equally effective. As a self-management tool it would therefore be less costly to administer with written instructions for reviewing the feedback, as this would eliminate the requirement for a trained facilitator to be present. Similarly it would also allow individuals to review their feedback in a wider variety of settings than if a facilitator were needed.

However, it should also be considered that this equality of effect may not hold true when feedback delivery is by someone other than that the researcher in this particular study. Given a larger sample and further resources, it would be valuable to test the efficacy of the feedback with a variety of deliverers e.g. practice nurses, counsellors, or those in coaching roles, to determine whether any differential effects may be related to the type of individual providing the feedback.

5.4.3 *Ill versus healthy*

As expected, the main effects analysis had confirmed a significant difference in subjective health status, in terms of the WHOQOL-BREF Physical Health domain and the EQ-5D VAS, between those who were chronically ill and those who were healthy, but there was no significant difference in terms of reported psychological health. This was surprising, as it disagrees with some previous studies which have found both the physical and psychological QoL of people with chronic illnesses to be less good than for healthy individuals (Dickson, Toft, & O'Carroll, 2009; Owayolu, Owayolu, & Karadag,

2011; Salaffi, Carotti, Gasparini, Intorcia, & Grassi, 2009; Slatkowsky-Christensen, Mowinckel, Loge, & Kvien, 2007). However, a study of eight chronic medical conditions by Arnold et al, (2004) found more mixed results. Arnold and colleagues showed that patients with back problems, rheumatoid arthritis and heart problems had lower physical QoL than healthy participants but only participants with lung disorders and migraine differed from healthy participants in terms of psychological health. They also found no differences for either physical or psychological QoL between healthy participants and patients with hypertension, diabetes or dermatological problems. This suggests that the type of illness may add complexity to the patterns of QoL difference between chronically ill and healthy participants.

Notably, scores on the GOSS-Q were also found to differ according to whether participants had a chronic illness or not. Although the scores of all participants suggested an overall movement towards QoL goals, that data suggested that this was more rapid for participants who were healthy. As this had not been previously tested, no prior hypothesis had been made and this finding remains tentative. However it would be interesting to test this assertion further in future studies.

It was also found that scores relating to the importance of physical health and the importance of psychological health were higher for healthy participants than for those with a chronic illness, although this was not true for the importance of social relationships or environmental QoL. These findings may however suggest an association between health status and importance which is worthy of further investigation. For example, it would be helpful to explore the effects of chronic illness on the ratings of the importance of QoL and to include investigation of response shift in these circumstances. As discussed in Chapter 2, response shift has been established to be an important mechanism in adaptation to illness (Schwartz, Andresen, Nosek, Krahn, & M, 2007; Schwartz et al., 2006; Sprangers & Schwartz, 1999). It is plausible that the effects changing internal standards, values and conceptualisations may be found to apply to subjective ratings of importance in much the same way as they are to ratings of core QoL.

5.4.4 The relationship between the importance of quality of life and core quality of life

The WHOQOL data revealed that importance scores were significantly higher than their respective QoL scores for the physical health, psychological health and environment domains at both time points. This might be indicative of a general tendency: that individuals rate the importance of these areas as higher on a scale than they do their QoL self-judgements. However, further analysis found that this was true only for those with a chronic illness whereas for those who were healthy, only the scores for the importance of psychological health were significantly higher than core QoL. This suggests a differential between the two groups: QoL was significantly lower than importance in more domains for people with a chronic illness than for healthy participants, indicating a greater discrepancy between actual and ideal QoL for the former group. However no significant gaps were evident between social domain core and importance scores for either group, suggesting that these dimensions were more closely aligned regardless of health status. The mode of feedback made little difference to the outcomes, which again may reflect the stability of the construct of importance.

What might have been expected to show a post-test effect would be the magnitude of gap between QoL and Importance. If Importance increased relative to QoL ratings, it might imply an increasing dissatisfaction between current and desired states. Similarly a decreasing magnitude of gap might indicate increased satisfaction with, or acceptance of current QoL. However, the data showed no effects in terms of changes in the gap between WHOQOL-BREF and WHOQOL Importance over time.

5.4.5 Evaluation of perceptions of change

Despite the modest improvements in wellbeing evidenced in the primary and supplementary outcome measures, an interesting observation emerging from the study was that the majority of participants reported that they perceived the way they thought about their QoL had changed. In comments they made, it was clear that, for some (9% of respondents), consideration of QoL had been a novel experience or something that they did not do regularly. It is possible that the feedback could have created new conceptions of QoL or that cognitions about its various aspects had been altered as a

result of taking part in the study, albeit not to the extent that it was detectable by most of the outcome measures employed.

Furthermore a substantial proportion of participants (40%) stated that they felt their psychological health had changed and, for some, this was reflected in comments they made about how they felt more positive, or that taking part had given them opportunity to appreciate the positive aspects of their lives. This perceptual shift had not however translated into more tangible consequences in that changes in mood were not detected by the affect measure (PANAS), although some effect on negative feelings, as measured by the WHOQOL-BREF was found. In line with the quantitative findings discussed earlier, few participants felt their goals or expectations had altered and very few reported changes in relation to their social relationships or environmental QoL. However, while very few (9%) had reported changes in their physical health, the quantitative analyses had detected a modest increase in subjective judgements of physical health in the WHOQOL-BREF scores of the overall sample. This may be due to the level of detail elicited by the WHOQOL-BREF physical health domain questions. These questions asked about seven different facets of physical health (pain, medication, mobility, energy, sleep, activities of daily living, work capacity) compared to the evaluation of change question which asked participants only whether their physical health had changed as a result of taking part.

Despite reporting few tangible changes in their QoL, participants did however talk about their intentions to make change, both in terms of focusing differently and in terms of specific actions they wished to take. It could be implied that taking part in the study had engendered a sense of readiness to take action and this type of behavioural preparedness has been asserted to form the basis of many health behaviour models (Conner & Norman, 2005b).

5.4.6 Study limitations

A key limitation of the study was the absence of a control group against which to compare the scores of those receiving QoL feedback. Including a condition where participants completed the T1 and T2 questionnaires but did not receive a feedback intervention would have added rigour to the study in terms of its ability to test the direct

effects of receiving feedback on self-judgements of QoL. Resources were not sufficient to allow for inclusion of a control condition in the present research and thus only tentative associations between QoL feedback and scores on specific measures could be made. Future studies finding no effects in a control group, but effects in intervention groups would provide more conclusive evidence of the potential of QoL feedback.

It must also be considered that The WHOQOL-100 and WHOQOL-BREF have usually been administered in a pencil and paper format although, more recently, studies using the Internet or computer based formats to explore QoL have begun to be reported (Baumann, Ionescu, & Chau, 2011; Feller et al., 2005; Mason, Skevington, & Osborn, 2004; Skevington & Day, unpublished). In this study two different questionnaire administration methodologies were used – paper based and online. Whilst it must be recognised that the alternative methodologies may have had potential to introduce bias, a recent study by Chen et al. (2009) sought to test whether a web-based format of the WHOQOL-BREF would be equivalent to the paper-based version. They found no significant differences between domain scores in the two versions. Similarly paper and touch-screen versions of the EQ-5D VAS have been found to have equivalent properties (Ramachandran, Lundy, & Coons, 2008).

Another limitation relates to the finding that thinking about QoL was a novel experience for some participants. French and Sutton (2011) have indicated that when people are asked to complete questions about issues they have not previously considered, they may provide responses that are generated on the spot, on the basis of inferences from their broader knowledge. The implication is that in these circumstances, their responses may be based on normative understandings rather than genuine personal reflection. This assertion has considerable implications for the validity of QoL measures, and for any research involving assessing beliefs about issues not previously considered. As such it is an avenue of fruitful further investigation. Although participants in the present study were made aware in the participant information of the study topic and that they would be asked about QoL, giving more comprehensive information before may make the task less novel and thus reduce the potential for any distorting effect of spontaneous inferences.

It is also plausible that a self-selection bias may have operated in the present study, as participants opting to take part may have had a prior interest in QoL or self assessment. This may have reduced effect sizes, since participants may have already been self-aware. Indeed, when those who received verbal guidance were asked during the telephone conversation if they had learned anything, a frequent response was “no”, that there was nothing that had surprised them. However this was also possibly an inevitable consequence of the questionnaire completion. Rating aspects of QoL required individuals to firstly attend to, and acknowledge their individual views. As such they would not have been expected to be surprised at the information contained in the feedback. These factors might be considered potential attenuating factors in reducing the effect size of the feedback intervention. Similar conclusions have been reached in behaviour change studies. For example, the effects of planning interventions have been found to be limited by the prior plans that participants have already made, before taking part in the research (Sniehotta, 2009).

While the present study collected data from healthy individuals and from a heterogeneous sample of people with chronic illnesses, it was disappointing that sample sizes were such that it was not practicable to analyse subgroups of illness types. As such, conclusions were only able to be drawn at the highest level of analysis. With a larger sample it would be interesting to investigate any differential effects of feedback for individuals with different forms of chronic illness who might be differentially affected by factors such as pain, disability, mobility, impact on activities, fluctuation of symptoms (Arnold et al., 2004). It would also have been preferable to have been able to include age analyses in the study. Only age category data were collected and specific ages would have allowed for more sophisticated analysis using age as a covariate.

5.4.7 Reflections on the study methodology

5.4.7.1 Interpretation of the WHOQOL graphical summary profile

It was evident in the verbal guidance conversations that some participants found the facet labels confusing. This was especially the case for the facets listed as “cognitions” and “spirituality”, since these terms had not been used in the questionnaires themselves. In future applications of the feedback methodology it might therefore be appropriate to change the graph labels or to provide facet definitions in order to aid understanding.

However, it must be borne in mind that adding further documentation would make the interpretation of the feedback more burdensome, which may in turn have a deleterious effect on its efficacy. Further investigation of the most suitable approach should be decided in conjunction with patients or other potential recipients of the feedback, as advocated by Haywood et al. (2006).

Examination of the WHOQOL-BREF and Importance questionnaires texts revealed disparities in the terminology used for three items. Firstly, the “cognitions” question in WHOQOL-BREF asks about ability to concentrate whereas the related question in the WHOQOL Importance questionnaire asks about thinking through problems and decision-making. Although these both reflect the construct “cognitions”, some participants may have found it difficult to assimilate when illustrated together on the graphical profile. Similarly, the “support” question in WHOQOL-BREF is about support from friends whilst the related question in the WHOQOL Importance questionnaire asks about support from others. Finally, the “spirituality” question in the WHOQOL-BREF asks about the extent to which life is felt to be meaningful. In the WHOQOL Importance questionnaire, the question asked refers to the importance of personal beliefs. It was decided not to amend either of the WHOQOL questionnaires prior to the study as the preference was to use the standard measures that had been systematically developed by the WHOQOL Group and which had been psychometrically tested and validated. However, to the best of knowledge, the two WHOQOL instruments have not previously been used together in the type of methodology explored here. Future applications may benefit from further consideration of these issues, at least to enhance the face validity and acceptability of the feedback from the perspective of the individual receiving it.

5.4.7.2 Recommended amendments to the verbal guidance script and written instructions

A practical reflection emerging from the operationalisation of the methodology was that additional guidance should be added to both the verbal guidance script and the written instructions to clarify the implications of any gaps between QoL scores and Importance scores. For example, where a QoL score is lower than its associated Importance scores, it should be made clear that this gap can be reduced in two ways:

- a) by improving QoL, AND/OR
- b) by reducing the importance the individual attaches to that topic.

This may be especially pertinent for some cases of physical health problems or necessary medication regimes where QoL cannot, or should not, be altered. For example, reducing pain or improving mobility may be impossible through personal volition, yet going to see a doctor for more analgesics or seeking a walking stick would be feasible and effective. At the same time, attempting to reduce the gap by making the topic less important would be an appropriate psychological endeavour and could be achieved through addressing current perceptions and beliefs.

Another recommendation following the study was to include more detail in the scale description for the facets. Rather than simply pointing out that a score of 1 indicates very poor QoL and 5 indicates very good, including 3 as a moderately good QoL level might assist in communicating the feedback information. Further to this, in describing the domains of QoL in relative terms, it might be more appropriate, in some cases, to use the terms “better QoL”, “more important”, “less good QoL” and “less important” than “good QoL”, “high importance”, “poor QoL” and “low importance”. For example, in a profile where all QoL domain scores or domain importance scores are above 50, only the *relative* “goodness” or “importance” might be relevant.

Towards the end of the feedback protocol, instructions were specifically designed to draw participants’ attention to the more positive aspects of their QoL by highlighting facets where both QoL and importance are high. In future applications it may be more helpful to draw attention to any facets where QoL is high, even if importance is lower, as these still reinforce positive messages.

5.4.7.3 *Design limitations*

Another limitation of the study stemmed from the pre-post test design (T1 and T2). In a number of the verbal guidance telephone calls, it was apparent that participants might have anticipated the purpose of the repeated measures design. It proved difficult to disguise this, especially as the T2 questionnaire pack included direct repetitions of several of the T1 measures and this had been sent to participants at the same time as

their feedback graphs. In order to try to minimise any confounding of the T2 results, participants were accordingly asked to not look at the graphical summary profile post feedback until after they had completed the second questionnaire pack. Future electronic administration could include a mechanism for the graphical summary profile to be hidden after feedback and not accessible again until the T2 questionnaires have been completed and submitted.

It was also the case that the two experimental conditions were not matched for timing of the intervention. Those in the verbal guidance group were sent their graphical summary profile 1-2 days prior to the telephone call to discuss their feedback. This potentially gave them time to look at the profile without waiting for verbal guidance and then to review it a second time during the subsequent telephone call when the guidance was provided. Conversely participants in the written instructions group were sent their graphical summary profile at the same time as the instructions and may have chosen to attend to their feedback immediately, reviewing it only once. This difference in methodologies may have introduced a potential limitation. Asking participants to refrain from looking at the graphical summary profile until it was appropriate to do so in combination with verbal guidance or written instructions (depending on their experimental group) may have helped in this regard.

As discussed earlier in section 5.2.4 of this chapter, for two participants with a particularly poor QoL an alternative verbal guidance script was deemed appropriate. In practice this was appeared satisfactory and no concern or distress was evident for those few participants during the feedback process. In future use, screening for moderate to high anxiety or depression levels could help to identify where the alternative script may be more appropriate or where alternative approaches, such as counselling, might be also be considered.

5.4.8 Relating findings to self-regulation theory

The findings of this study should also be considered within the context of Carver & Scheier's (1998) SRT. Reviewing the results within this framework, a number of possible inferences emerge:

It is possible that, for at least some of the sample, the feedback received was insufficient to bring about a comprehensive perception or sensing of their present condition, thus suggesting the input function stage of the SRT feedback loop was not fully activated. However, the findings of the T3 questionnaire would suggest that this might only have been so for a minority of participants, as most had reported that they perceived the way they thought about their QoL had changed in some way.

As in the previous study, participants were asked to think about their QoL, mood and extent to which they were achieving goals in the present. The reference value element of the feedback loop, identifying what is desired or intended (i.e. goals), was intended to be provided by inclusion of the importance scores from the questionnaires. This was achieved and participants reported that they had thought about the gaps between their current QoL and what they desired, in line with the compactor component of the feedback loop. However, the development of concrete plans and goals or changes in behaviour (i.e. the output function) was not specified or requested from participants. Indeed, the concept of “plans and expectations” was only mentioned in the T3 questionnaire. Consequently, even if completion of the earlier feedback loop stages had been achieved, participants may not have spontaneously gone beyond this to take actions towards meeting their goals or expectations (the output function of the loop). Possible additional components related to the development of goals, which might serve to support the output function, will be discussed in Chapter 8. Nevertheless the data in the present study suggested that, for a number of participants, taking part had led them at least to begin to consider what changes they could or should make.

SRT also suggests that, along with behaviour guiding cognitions, feelings also are engendered as a result of monitoring the success of discrepancy reducing efforts. That the participants in the study did not achieve completion of all elements of the feedback loop may help to explain why no T2 improvements were found in mood (as measured by the PANAS).

In summary, the modesty of T2 changes can be accounted for in terms of SRT by the absence of full completion of the feedback loop. As such SRT provides a plausible explanation for the findings of this study.

5.4.9 Looking ahead

The findings of this study suggest that receiving feedback on subjective judgements can lead to changes in consideration of subjective QoL and, in particular, can bring about small, but significant improvements in psychological wellbeing. This may be an important precursor to seeking to make behavioural changes that could further capitalise on this improved wellbeing and ensure longevity of effect. As has been previously found, without such additional efforts, these beneficial effects may be lost over time (De Wit et al., 2010). It is also plausible that psychological QoL change is a necessary foundation upon which changes in physical, social and environmental QoL can subsequently be built. Investigating this with studies over longer timescales may be helpful in testing this proposition.

In addition, the successful implementation of QoL feedback to bring about a sustained beneficial effect is likely to depend on the degree to which the context in which it is applied is appropriate and supportive. For example, in the case of the chronic care model, it was determined that for it to be successful, conditions must be favourable to support the model in terms of the general community, the health care system, and the institution itself (Bodenheimer, Wagner, & Grumbach, 2002). This has important implications for the settings in which QoL feedback might be utilised and thus for the development of this methodology in applied contexts. Even within these contexts, it is also necessary to determine which individuals should be involved in the administration of the feedback as there may be particular skills involved in implementation of the methodology that are instrumental critical to its success. Further investigation with professionals already giving other types of feedback, perhaps using cognitive interviewing techniques, would help to identify the required skills and therefore the identification of who the appropriate administrators should be. The development of a training programme for the critical skills would also help to ensure consistency of standards and allow administration by individuals not previously experienced in providing feedback.

5.4.10 Conclusion

The results of this study suggested that an intervention providing individualised feedback on subjective judgements of QoL was associated with changes in wellbeing in

terms of increased scores relating to psychological health (as measured by the WHOQOL-BREF). Results showed no difference according to whether verbal guidance was provided to review the feedback or whether the feedback was independently reviewed according to written instructions, suggesting either method was equally effective. Additional efforts are needed to enhance the efficacy of feedback by incorporating the identified methodological enhancements. Further testing would then establish whether the positive effects found can be extended to other dimensions of QoL.

CHAPTER 6. PSYCHOMETRIC PROPERTIES OF THE QUALITY OF LIFE INSTRUMENTS

6.1 Introduction

Applying QoL outcome measures with individuals requires high calibre instruments. These need to be precise in their assessments if they are to reliably assess individuals' QoL, in the same way as groups can be assessed (Skevington & McCrate, 2012). It is especially important to ascertain the accuracy of instruments if their psychometric properties are not already known. In the case of the present study, establishing the psychometric properties of the QoL measures used in the feedback intervention would tell us whether the results discussed in earlier chapters were accurately measured and whether they can confidently be used in future studies. Moreover, finding that the QoL measures have good psychometric properties would support their application both for individual assessment and for one-to-one use. The aim of this investigation was, therefore, to test the properties of the QoL instruments used in the earlier chapters of this thesis and to investigate their complementarity.

Consideration of internal consistency is one approach to establishing the reliability of a psychometric instrument. Cronbach's alpha (α) estimates reliability, based on all possible correlations between the items in a scale, and is recommended as a measure of internal consistency (Bowling, 2005c). As discussed in more detail in Chapter 3, the internal consistency of the WHOQOL-BREF has consistently been demonstrated to be good and while few studies have reported the psychometric properties of the WHOQOL Importance scale, those which have done so have suggested it to be good also (Molzahn et al., 2011; Molzahn et al., 2010; Saxena et al., 2001) .

It is also asserted that in conducting psychometric assessments, the factor structure of measurement tools should be assessed as a measure of construct validity (Bowling, 2005c). Where a theory about a structure already exists, factor analysis (FA) is a traditional approach to understanding the underlying dimensions of a scale, identifying items that cluster together to form sets of variables or factors. FA allows comparison of

the hypothesized structure and the factor solution. In this way findings can be compared with the original theoretical model to see how closely the observed pattern corresponds (Streiner & Norman, 2008). Principal Components Analysis (PCA) is a form of factor analysis where the correlations among variables are also used to transform the data into a smaller set of unrelated components (Dancey & Reidy, 2004). These components are assumed to reflect the hypothetical constructs of the instrument, but describe their relationship rather than providing a theoretical analysis. In both approaches, as well as conducting exploratory investigations, the number of factors can be fixed according to what the researcher thinks the final structure should look like. To the best of knowledge, no studies exist which have previously applied PCA to the WHOQOL Importance and GOSS-Q instruments.

Correlations between the variables within instruments can also be calculated as a measure of construct validity. Whilst these are often recorded in the published results of studies, not many prior studies have directly compared the performance of the WHOQOL-BREF and the EQ-5D VAS, although the few that have done so, suggest correlations between the two instruments (Günther, Roick, Angermeyer, & König, 2007; König et al., 2010). For example, in a study of anxiety disorder patients in Germany, König et al. (2010) found strong associations between the EQ-5D VAS and the physical health domains of the WHOQOL-BREF, a moderate association with the psychological domain and small associations with the environment domain.

There has been limited interest in the importance of dimensions of QoL, but this has yet to be systematically investigated in terms of psychometric properties. While a handful of investigations have looked at importance cross-culturally (Molzahn et al., 2011; Saxena et al., 2001) and in relation to the identification of the poorest QoL (Skevington & O'Connell, 2004), none have specifically set out to test this instrument against other non-WHOQOL measures. Only one study has tested correlations between the WHOQOL-BREF and WHOQOL Importance items, finding little association between the two instruments (Skevington & O'Connell, 2004). An opportunity therefore exists to provide new and original data to help establish the psychometric properties of the WHOQOL Importance.

Despite the fact that gender and age are important markers for individual differences in psychosocial variables, an extensive literature search found only very few prior studies which had used the WHOQOL-BREF to directly compare men and women's QoL or to compare scores across different ages. One study of age and gender differences among Portuguese HIV-infected patients found that women reported lower Psychological QoL than men, and that when the sample was divided into quartiles by age, younger patients reported higher QoL than older patients on the Physical Health domain (Pereira & Canavarro, 2011). Another study of Chinese women with cervical cancer, where participants were divided into young adulthood (18–45 years), midlife (46–65 years), and old age (66 years or above), found that QoL in the Social Domain deteriorated with age (Lai & Tang, 2009). Otherwise, outside the WHOQOL Group's own work (Skevington, Lotfy, et al., 2004; The WHOQOL Group, 1995, 1998a, 1998b), there exists limited research into the influence of age and gender on WHOQOL-BREF scores.

The GOSS-Q was adapted for the present programme of research. As such it had yet to be tested, affording an opportunity to provide an initial exploratory assessment of its psychometric properties.

6.1.1 Hypotheses

Using Cronbach's α as the primary measure of reliability, it was expected on the basis of prior evidence that both the WHOQOL-BREF and WHOQOL Importance instruments would demonstrate good internal consistency in this study. However, as the GOSS-Q is an adapted instrument and no prior data were available it was not possible to make a definitive *a priori* hypothesis relating to this measure. However the Cronbach's α of the original GOSS scale has been reported as .80 (Dibb & Yardley, 2006) and .81 (Yardley & Dibb, 2007) and it was therefore expected to be broadly similar in the present study.

Applying FA on the WHOQOL-BREF, and PCA on the WHOQOL Importance and the GOSS-Q instruments it was anticipated that the WHOQOL-BREF would conform to either to its defined four-domain structure, or to one which represented the original six-domain model of the WHOQOL-100, from which it was derived. It was further anticipated that the WHOQOL Importance data would also largely conform to the domain structure of the WHOQOL model, given that it is embedded in the development

work of the WHOQOL-100 instrument and stems from the same data as the WHOQOL pilot field study (Saxena et al., 2001). As mentioned above, no prior research exists regarding the GOSS-Q, so again no definitive hypotheses were made regarding its structure. However, given that the items within the adapted version were specifically designed to reflect the six factor model of the WHOQOL-100, it was thought plausible that the related six items in the GOSS-Q might either remain independent or that they would cluster onto a single factor to reflect the overarching construct of the instrument (QoL-related goal orientation).

As discussed earlier, the existing literature has established the strong psychometric properties of the WHOQOL-BREF, and so it was anticipated that it would demonstrate good discriminative validity for categories of health status, i.e. groups with low health status should have lower WHOQOL-BREF scores than those with higher health status (Streiner & Norman, 2008). This was particularly expected to be the case when health status was determined by the WHOQOL overall health question from within the same measure. The more robust test using EQ-5D VAS scores to determine health status groups was however, also expected to show that the WHOQOL-BREF has good discriminative validity. No predictions were made about the ability of the WHOQOL Importance to discriminate against categories of health status as this had not previously been tested.

Building on the limited prior evidence regarding correlations between the WHOQOL-BREF and the EQ-5D VAS, and because both instruments are assessments of the same construct i.e. health related QoL, it was expected in the present study that significant and moderate correlations would be found between the two. It was further predicted that this would be particularly in terms of association between the EQ-5D VAS and the Physical Health domain of the WHOQOL-BREF.

QoL-related goal orientation, as assessed by the GOSS-Q was also expected to correlate with the WHOQOL-BREF, as the GOSS-Q was adapted to measure orientation towards specific QoL goals, although this association had not been previously tested. Given the lack of prior literature regarding the association the GOSS-Q and other instruments, these correlations were considered exploratory and no prior hypotheses were made. This was also true for predictions of correlations within the domains of the GOSS-Q.

As no prior studies have previously investigated correlations between the WHOQOL Importance and other non-WHOQOL instruments again no predictions were made prior to the analyses. It was, however, expected that correlations within the WHOQOL-BREF and within the WHOQOL Importance would be moderate to strong as these were derived from the same source and have both been shown to have strong psychometric properties (Saxena et al., 2001; Skevington, Lotfy, et al., 2004; The WHOQOL Group, 1998b).

This chapter therefore presents data to confirm and extend findings about the properties of the WHOQOL-BREF and EQ-5D VAS as well as to offer new insights relating to these and the less researched instruments: the WHOQOL Importance and the GOSS-Q.

6.1.2 Aims

To examine the psychometric properties as fully as possible the analyses in the present chapter aimed to examine the data for (a) the internal consistency of the instruments; (b) the goodness-of-fit of the WHOQOL and GOSS-Q instruments with their hypothesised respective models; (c) the convergent validity of the instruments and the within-instrument correlations between their respective domains; (d) the discriminative validity of the WHOQOL instruments, and finally (e) the effects of age and gender on the WHOQOL measures. Test-retest reliability was not able to be performed as, where T2 data were available from the earlier studies, these were repeated measures after a deliberate intervention had taken place and which had been intended to bring about a subsequent effect on instrument scores. However, previous research has indicated that test-retest reliability for the WHOQOL-BREF is good (Skevington & McCrate, 2012; Steinbüchel, Lischetzke, Gurny, & Eid, 2006; The WHOQOL Group, 1998a; Van Esch et al., 2011). Similarly the test-retest reliability of the EQ-5D VAS has also been established (Hurst, Kind, Ruta, Hunter, & Stubbings, 1997; Janssen, Lubetkin, Sekhobo, & Pickard, 2011; Stark, Reitmeir, Leidl, & König, 2010).

6.2 Method

6.2.1 Study outline

This chapter investigates the psychometric properties of the QoL related measures used in the previous three chapters: the WHOQOL-BREF and WHOQOL Importance scales, the EQ-5D VAS and the GOSS-Q. The PANAS is not included as this is a measure of mood rather than QoL. Different versions of the EQ-5D descriptive system had been used in studies 2 & 3 (as a new version had been published by EuroQoL part way through the research for this thesis) and these data were therefore not included in the analysis for this chapter.

The data analysed and presented in the present study were taken from Studies 1, 2 and 3 of the research programme, presented in Chapters 3, 4 and 5. The inclusion and exclusion criteria for these studies were discussed previously, together with their respective recruitment methodologies and attrition characteristics.

6.2.1.1 Data preparation

T1 data from previous studies were combined to provide as large a sample as possible for the psychometric analyses in the present analyses. Table 6.1 shows the numbers of participants in each study who completed one or more of the measures examined in the present study: Study 1 participants completed only the WHOQOL instruments; participants in Study 2 completed the WHOQOL-BREF, EQ-5D VAS and GOSS-Q, but not the WHOQOL Importance measure; and participants in Study 3 completed all measures.

Prior to analyses, the data relating to WHOQOL domain scores (BREF and Importance), total GOSS-Q scores and the EQ-5D VAS scores were examined for missing data and extreme values. Missing data were replaced and extreme scores adjusted following the methods previously detailed. Normality indices showed satisfactory levels of skewness and kurtosis and variables were within the recommended range of ± 1 (Hair et al., 1999).

Table 6.1 Numbers of participants in each of Studies 1, 2 and 3 completing each of the QoL measures

Study	Total participants	WHOQOL-BREF	WHOQOL Importance	EQ-5D VAS	GOSS-Q
1	9	9	9	0	0
2	26	13	0	25	26
3	165	165	165	164	165
Total	200	187	174	189	191

Because of the particular sensitivity of PCA to outliers, data screening was also performed for the individual item scores within the instruments' domains. Five cases of multivariate outliers were removed, and those remaining with z -scores $> \pm 3.29$ were adjusted following Field (2005), whereby scores are calculated back from z -scores ($X = (z \times s) \pm M$). This was done for 5 cases for the WHOQOL-BREF, 9 cases for the WHOQOL Importance, and 2 cases for the GOSS-Q. Most items were within the recommended range for skewness. Tabachnick and Fidell (2001) recommend looking at the shape of the distribution of the data in large samples, rather than using formal inference tests, so histograms with normal distribution curves were inspected and were acceptable. Kurtosis was below the recommended (+1) range (Hair et al., 1999) for most items, with only one demonstrating positive kurtosis beyond this range. Following Tabachnick and Fidell (2001, p. 74) who point out that "*underestimates of variance associated with positive kurtosis... disappear with sample of 100 or more cases*", this was acceptable.

6.2.1.2 Data analysis

Internal consistency reliability for the WHOQOL-BREF, WHOQOL Importance and GOSS-Q scales was assessed using Cronbach's α . For both the WHOQOL-BREF and WHOQOL Importance tests the two general items (overall QoL and overall health) were excluded from the analysis as these might have erroneously inflated the α value of the scale. Streiner and Norman (2008) suggest α values of at least 0.7 should be considered acceptable and this criterion was adopted for the present study. It must be acknowledged that some psychometricians recommend that a criterion of Cronbach's α of at least 0.9

should be applied for measures applied at the level of individuals, rather than groups (Bland & Altman, 1997; Nunnally, 1978). However consensus about the application of strict criteria for person-centred outcome measures is currently a topic of debate in the QoL community (International Society for Quality of Life Research, 2012b).

FA was conducted on the individual facets in the WHQOL-BREF using a principal factors extraction technique to investigate whether the data reflected the hypothesised domains of the instrument. PCA was used to analyse the WHOQOL Importance data to examine the relationships between the constructs. Sample size was sufficient according to the criterion specified by Hinton (2004) which stipulates that a) a minimum of 200 scores should be present, made up of at least 10 scores per item and b) there should be at least five times as many participants as items. Initially an exploratory approach was utilised for 24 items in each scale (i.e. excluding the overall QoL and overall health items). Repetition of the analyses fixed the number of factors at four, to reflect the number of domains in the WHQOL-BREF model. PCA was also carried out on the GOSS-Q items to determine if these items related to one or more factors. In all analyses, factors were rotated using the Varimax method, in which axes remain orthogonal. This minimizes the overlap between factors and is asserted to produce more interpretable clusters of factors (Bowling, 2005c; Field, 2005; Kinnear & Gray, 2010). Following Kinnear and Gray (2010) listwise exclusion of missing data was specified, as this is a more stringent criterion than pairwise exclusion. To ensure that FA was appropriate for the dataset, the Kaiser-Meyer-Olkin (KMO) statistic for sampling adequacy was required to be at least 0.7 (the criterion specified as “good” by Kaiser (1974)). To indicate some degree of relationship between the variables, Bartlett’s test of sphericity was required to be significant (Field, 2005). However, given the sample size, it was anticipated that this would be the case as it is considered to be overly sensitive and to typically show significance when applied to large data sets, even when correlations are low (Kinnear & Gray, 2010; Tabachnick & Fidell, 2001). The importance of the factors was determined by examining the scree plots of the eigenvalues. However, it is not recommended that factor selection be based on this criterion alone and, following Kaiser’s criterion, factors with an eigenvalue greater than or equal to 1, were also included (Field, 2005; Kinnear & Gray, 2010). Factor loadings $>.4$ were retained in each model, as recommended by Stevens (1992). PCA was also conducted on the GOSS-Q as

an exploratory investigation to reveal any factor structure underlying this scale. The same method of rotation and criteria for model retention were applied.

The discriminative validity of the WHOQOL-BREF and WHOQOL Importance instruments was assessed by splitting the sample into groups indicative of poor, satisfactory, good and very good health status. To do this, the data were firstly examined in terms of scores of health status as measured by the general health question of the WHOQOL-BREF “*How satisfied are you with your health?*”. The five-point scale for this question was 1) very dissatisfied, 2) dissatisfied, 3) neither satisfied nor dissatisfied, 4) satisfied and 5) very satisfied. As only five cases had recorded “very dissatisfied”, it was decided to combine these with the next highest category “dissatisfied” to improve the distribution of the sample across the health status groups. Accordingly the data were recoded into four groups. One-way ANOVAs were used to test the main effects of health status group for each WHOQOL-BREF domain. These were repeated for the WHOQOL Importance domains. In line with recommendations, where the assumption of homogeneity of variance was violated, Welch’s *F* test was reported (Field, 2005). Post-hoc testing used the Games-Howell procedure as this is more accurate when sample sizes are unequal or when there is any doubt that population variances are equal (Field, 2005).

To examine the ability of the WHOQOL-BREF and WHOQOL Importance to discriminate between health status groups identified by scores on EQ5D-VAS, the sample was also split into four groups using frequency quartiles: EQ-5D VAS ≤ 65 (“poorest health”), ($N=50$); EQ-5D VAS $> 65 \leq 75$ (“poor health”), ($N=45$); EQ-5D VAS $> 75 \leq 87$ (“moderately good health”), ($N=48$); and EQ-5D VAS > 87 (“best health”), ($N=46$).

To investigate concurrent, convergent and construct validity, Pearson’s bivariate correlation analysis was used to measure the association between the domains within the WHOQOL-BREF, WHOQOL Importance and GOSS-Q instruments, as well as between the domains of each of these scales and including the EQ-5D VAS. Strengths of correlations were interpreted as follows (Dancey & Reidy, 2004):

$0.1 \geq r < .4 = \text{weak}$
 $0.4 \geq r < .7 = \text{moderate, and}$
 $0.7 \geq r = \text{strong.}$

Bivariate correlation was also applied to examine the relationship between scores on the EQ-5D VAS and responses to a demographic question attached to the WHOQOL-BREF “*Are you currently ill?*” to which possible responses are “yes” or “no”. This correlation is recommended when one of the two variables being examined is dichotomous (Field, 2005). (The point-biserial correlation coefficient was not used, as this only applies when the dichotomous variable is strictly discrete, rather than when it is a continuous dichotomy such as is the case in categories of “ill or well”.) It was intended that this analysis would reveal any relationship between how self-judgement of health status (on a 0-100 scale) related to the classification of “ill” or “well”. One-tailed significance tests were used as it was expected that “well” cases would have rated themselves as having better health on the EQ-5D VAS.

The WHOQOL data were also examined at the domain level in terms of gender and age using MANOVA. The data were dichotomised into younger (ages 18-44) and older (age 45+) adults, as this categorisation had been adopted in previous quota sampling strategies and in psychometric analyses of the WHOQOL-BREF and WHOQOL-100 (Skevington, 1999; Skevington, Lotfy, et al., 2004; Skevington & O'Connell, 2004; The WHOQOL Group, 1998a). The assumptions of MANOVA were checked following Field (2005). Firstly homogeneity of variance was confirmed by non-significance of the Levene's test, which supports the assumption that the multivariate test was robust. Secondly the variance-covariance matrices were compared using Box's test. This test examines whether the correlation between two dependent variables is the same in all groups and again should be non-significant, otherwise the robustness of the test would be considered problematic. A non-significant score indicated the assumption had not been violated. As groups sizes were unequal for both age and gender, Pillai's trace was reported as the test result Field (2005).

Within the analysis, multiple comparisons were conducted so that a breakdown of any significant differences between independent variables (age and gender) and dependent variables (WHOQOL-BREF and WHOQOL Importance domains) could be observed.

Bonferroni corrections were applied in the analyses to ensure that the cumulative Type 1 error remained below .05 throughout (Field, 2005). Assessment of effect size used J. Cohen's (1988) guidelines for the interpretation of F and equivalent values of partial eta squared (η^2), whereby $0.01 \leq \eta^2 < 0.06$ = small; $0.06 \leq \eta^2 < 0.14$ = medium; and $\eta^2 \geq 0.14$ = large (Kinnear & Gray, 2010).

Post-hoc independent t tests were also used to assess differences between groups for the GOSS-Q instrument. Homogeneity of variance was assumed except where indicated otherwise by the Levene's test statistic. In these cases the "equal variances not assumed" t test result was consequently accepted and reported (Kinnear & Gray, 2010).

Unless stated otherwise, results are reported as significant throughout the present study where $p < .05$.

6.3 Results

The total sample in this analysis consisted of 200 participants. Within this there were 131 (66%) females and 68 males (34%), plus one individual whose gender was undisclosed. Ages of participants according to the categories defined in Study 3, are given in Table 6.2 together with the other demographic characteristics of the sample. As can be seen, there was a satisfactory distribution across most age categories ranging from 12% to 19% of the sample in each category, with the exception of the 18-24 years category but this had a smaller age range and contained only 6% of the sample. As in previous studies, the majority of participants (62%) had received a college, university or postgraduate education. Of the participants, 63% were either married or had a partner.

6.3.1 Mean scores and standard deviations of the measures

Mean scores and standard deviations of the subscales of all measures are given in Table 6.3. Mean domain scores on the WHOQOL-BREF indicated highest QoL in relation to Environment, and lowest in relation to Psychological Health, although at 64.78, this still indicated good QoL. In terms of the WHOQOL Importance domains, Physical Health was scored as most important, with Social Relationships as least important (again a

score of 50 is the mid-point of the scale, indicating moderate importance). None was unimportant.

Table 6.2 Demographic characteristics of psychometric study participants

		<i>N</i>	% of total sample (<i>N</i> =200)	% of valid sample
Age	18-24	12	6.0	6.2
	24-34	32	16.0	16.4
	35-44	23	11.5	11.8
	45-54	33	16.5	16.9
	55-64	36	18.0	18.5
	65-74	31	15.5	15.9
	75+	28	14.0	14.4
	Missing	5	2.5	
Gender	Male	68	34.0	34.2
	Female	131	65.5	65.8
	Missing	1	.5	
Education	Primary	1	.5	.5
	Secondary	45	22.5	23.0
	Technical / Further Education	28	14.0	14.3
	Higher Education / University	52	26.0	26.5
	Post-graduate	70	35.0	35.7
	Missing	4	2.0	
Marital status	Single (never married)	34	17.0	17.3
	Married	97	48.5	49.5
	Partnered (not married)	26	13.0	13.3
	Separated / divorced	24	12.0	12.2
	Widowed	15	7.5	7.7
	Missing	4	2.0	

Table 6.3 Mean scores and standard deviations for the WHOQOL measures, GOSS-Q and EQ-5D VAS

Measure	<i>N</i>	Mean	<i>SD</i>
WHOQOL-BREF Domains			
Physical health	184	68.78	20.47
Psychological health	185	64.78	15.57
Social Relationships	187	67.04	19.56
Environment	186	75.04	14.85
WHOQOL Importance Domains			
Physical health	172	79.74	11.58
Psychological health	174	75.32	13.13
Social Relationships	174	69.06	17.38
Environment	174	78.76	11.84
GOSS-Q Domains			
Physical	191	3.91	1.28
Psychological	191	4.36	1.12
Social	191	4.20	1.19
Environment	191	4.47	0.99
Independence	191	4.29	1.32
Spiritual	191	4.50	1.02
EQ-5D VAS	189	73.12	18.02

QoL-related goal orientation was highest in the Spiritual domain, indicating that this was the aspect of ideal QoL towards which the sample felt they were moving most quickly. (On the 1 – 7 scale, 1 = moving very quickly away from ideal QoL; 4 = not moving at all; and 7 = moving very quickly towards. (See Chapter 4, section 4.2.4 for further information). The only domain whose mean was below the “not moving at all” score of 4, was Physical Health where the mean score indicated movement slowly away from ideal Physical QoL. The mean score on the EQ-5D VAS was 73 on the 0 -100 scale indicating good health (see Chapter 4, section 4.2.4 for further information on this measure).

6.3.2 *Tests of the internal consistency reliability of the WHOQOL-BREF, WHOQOL Importance, GOSS-Q and EQ-5D VAS*

Details of Cronbach's α for each measure are given in Table 6.4. As discussed in section 6.1.1, on the basis of previous evidence it was predicted that values would be high. For the WHOQOL-BREF as a 24-item scale, the value for Cronbach's α was found to be very high (.92). Furthermore, examination of the item substitution procedures revealed reliability would not have improved had any of the individual items been removed. In addition, Cronbach's α was found to be acceptable for three of the WHOQOL-BREF domains: Physical Health (.86), Psychological Health (.82), and Environment (.84). For the Social Relationships domain Cronbach's α was marginally acceptable (.69).

Table 6.4 Internal consistency of the WHOQOL-BREF, WHOQOL Importance and GOSS-Q as shown by Cronbach's α 's for scales and domains

Measure	<i>N</i>	α
WHOQOL-BREF (total scale)	164	.921
Physical health	179	.860
Psychological health	182	.815
Social Relationships	176	.693
Environment	184	.840
WHOQOL Importance (total scale)	157	.873
Physical health	169	.644
Psychological health	172	.766
Social Relationships	168	.557
Environment	167	.771
GOSS-Q (total scale)	191	.854

Cronbach's α for the WHOQOL Importance scale was also found to be acceptable (.87). Three items were identified whose removal would have improved reliability. These were medication, work and sex life. For each of these, removal of the item would have resulted in an increase in overall α from .87 to .88. Results for the WHOQOL Importance domains showed that Cronbach's α was acceptable for two domains: Psychological Health Importance (.77) and Environment Importance (.77) but it was not acceptable (.64) for Physical Health Importance and Social Importance (.56). This result

indicated that the domains within the WHOQOL Importance scale were less consistent than those of the WHOQOL-BREF.

The value of Cronbach's α for the GOSS-Q was acceptable (.85) although it was also found that removal of the spiritual item would have had the effect of increasing this value from .85 to .86.

6.3.3 Tests of the construct validity of the WHOQOL-BREF, WHOQOL Importance and GOSS-Q instruments

6.3.3.1 WHOQOL-BREF

FA was conducted on the 24 facet items of the WHOQOL-BREF to investigate the theoretical underlying structure of the scale. The Kaiser-Meyer-Olkin score (.88) indicated that sampling adequacy was good and Bartlett's test of Sphericity confirmed that factor analysis was appropriate ($\chi^2 (df = 276) = 1695.88 p < .001$). The scree plot of the FA indicated the dominance of the first component and indicated the retention thereafter of the next 2 factors. However, the FA yielded six factors with eigenvalues >1 which together explained a total of 64% of the variance. Factor loadings are presented in Table 6.5.

In the rotated model of the Kaiser-criterion generated six factor solution, the first factor contained four WHOQOL-BREF Physical Domain items and explained 11% of the variance. The second factor of five items contained all three Social Domain items (relationships, support and sex), one Environment Domain item (home environment), and one Psychological Domain item (spirituality). Together these accounted for 9% of the variance. Items loading onto the third factor (9% of the variance) were all from the Environment Domain of the WHOQOL-BREF. The fourth factor (8% of the variance) contained four items: two from the Psychological Domain (cognitions and positive feelings); one from the Physical Domain (sleep) and one from the Environment Domain (safety). The fifth factor (8% of the variance), contained three items from the Psychological Domain: self-esteem, negative feelings, and body image. The final factor contained two high item loadings, both from the Physical Domain: pain and medication. As predicted, this six factor model was mostly consistent with the theoretical WHOQOL-BREF domain structure in terms of the clustering of items around the four

domains: physical, psychological, social and environment, although home environment and spirituality also cross loaded to the social factor. However, the model also showed two additional factors, one with a mix of items from different domains and the other forming a “medical” factor (pain and medication).

Table 6.5 Rotated factor loadings of the items in the WHOQOL-BREF

<i>N</i> = 160	Component					
WHOQOL-BREF Facet	1	2	3	4	5	6
Mobility	.747					
Activities	.678					
Work	.643					
Energy	.589					
Relationships		.649				
Support		.610				
Sex		.471				
Spirituality		.445				
Home environment		.442				
Health care			.630			
Information			.550			
Finances			.471			
Physical environment			.445			
Recreation			.441			
Transport			.417			
Positive feelings				.509		
Cognitions				.507		
Safety				.505		
Sleep				.405		
Self-esteem					.620	
Negative feelings					.578	
Body image					.495	
Medication						.764
Pain						.587
Initial Eigenvalues	8.33	1.99	1.47	1.26	1.13	1.09
Rotated % of variance	10.64	9.34	9.14	8.11	8.04	6.42

Table 6.6 Fixed factor rotated loadings of the WHOQOL-BREF items

<i>N</i> = 160	Component			
WHOQOL-BREF Facet	1	2	3	4
Activities	.763			
Mobility	.722			
Energy	.622			
Medication	.617			
Work	.614			
Pain	.526			
Relationships		.639		
Home environment		.587		
Spirituality		.557		
Support		.527		
Sex		.429		
Self Esteem			.658	
Negative feelings			.605	
Positive feelings			.566	
Body image			.464	
Health care				.629
Information				.573
Finances				.475
Recreation				.457
Physical environment				.438
Initial Eigenvalues	8.33	1.99	1.47	1.26
Rotated % of variance	14.56	12.10	10.12	8.81

FA was repeated specifying a fixed factor model of 4 factors to reflect the number of domains in the WHOQOL-BREF. In this model the four components explained 54% of the variance and again the scree plot indicated retention of the first two factors. The factor loadings of the model are presented in Table 6.6. The first factor accounted for 15% of the variance in the rotated model and contained six of the eight items in the

Physical Domain of the WHOQOL-BREF. A seventh Physical Domain item, sleep, had a factor loading of 3.87, which was marginally below the recommended criterion of .4.

The second factor (12% of the variance) contained the three Social Domain items: relationships; support and sex; the home environment item from the Environment Domain and Spirituality from the Psychological Domain. The Transport item from the Environment domain had also loaded to this factor but was below the .4 criterion.

The third factor (10%) contained four items, all from the Psychological Domain: self-esteem, negative feelings, positive feelings and body image. One other Psychological domain item (cognitions) also loaded to this factor, but below the recommended criterion. The fourth and final component contained only items from the Environment Domain, which together accounted for 9% of the variance.

The results from the fixed factor model showed a structure very similar to the domain structure of the WHOQOL-BREF supporting the prediction of a good fit with the hypothesised model. Two items from other domains (home environment and spirituality) again cross-loaded to the social factor otherwise Physical domain items loaded onto factor one, Social domain items onto factor 2, Psychological domain items onto factor 3 and Environment domain items onto factor 4. Testing the scale in this way confirmed the theoretical structure of the instrument.

6.3.3.2 *WHOQOL Importance*

PCA was conducted on the 24 facet items of the WHOQOL Importance Instrument to investigate the correlations among the variables to see how they grouped together. The Kaiser-Meyer-Olkin score (.79) indicated that sampling adequacy was good and Bartlett's test of Sphericity confirmed that factor analysis was appropriate ($\chi^2 (df = 276) = 1137.25$ $p < .001$).

The first exploratory PCA yielded seven components which together explained a total of 61% of the variance although the scree plot suggested two meaningful components. Component loadings of those seven items that met the Kaiser criterion of eigenvalue >1 are presented in Table 6.7. Component one of the rotated model contained six items

which together accounted for 13% of the variance. The items were all from the Environment Domain of the WHOQOL Importance.

Table 6.7 Rotated factor loadings of the items in the WHOQOL Importance

<i>N</i> = 152	Component						
WHOQOL Importance Facet	1	2	3	4	5	6	7
Finances	.751						
Home environment	.646						
Health care	.644						
Safety	.640						
Transport	.623						
Physical environment	.418						
Self Esteem		.627					
Positive feelings		.618					
Spirituality		.610					
Information		.604					
Energy		.478					
Negative feelings		.427					
Relationships			.803				
Support			.740				
Sex			.486				
Sleep				.756			
Cognitions					.656		
Mobility					.627		
Activities					.525		
Medication						.633	
Pain						.568	
Body image						.431	
Work							.788
Recreation							.502
Initial Eigenvalues	6.25	1.92	1.55	1.42	1.23	1.16	1.04
Rotated % of variance	13.07	11.09	9.02	7.50	7.25	6.59	6.21

The second component contained six items (11%). Four were from the Psychological Domain (self-esteem, positive feelings, negative feelings and spirituality), one (information) was from the Environment Domain and one from the Physical Health Domain (energy). The three items in the third component (9%) matched the three items in the Social Domain. The fourth component contained only a single item: sleep, which accounted for 7% of the variance. Two items contained in the fifth component, mobility and activities were from the Physical Health Domain whilst the third, cognitions was from the Psychological Domain. Together these also accounted for 7% of the variance. The sixth component (7%) contained the pain and medication items from the Physical Health Domain plus body image from the Psychological Domain. Items in the final (7th) component, were both from the Environment Domain, and together accounted for 6% of the variance. Overall this model demonstrated a lack of fit with the WHOQOL-BREF domain structure and did not support the prediction made prior to the analyses that it would have a similar structure.

Repeating the PCA for the WHOQOL Importance whilst fixing 4 factors yielded a model which in which the four components explained 46% of the variance. The component loadings of the model are presented in Table 6.8. As with the exploratory PCA, the scree plot elbow indicated retention of the first two components. In the rotated model the first component accounted for 15% of the variance. It contained six items from the Environment Domain of the WHOQOL Importance, and mobility from the Physical Health Domain. The information item of the Environment Domain also loaded onto this component but, at .35, was below the recommended loading criterion for consideration of .4. The second component contained seven items (14% of the variance): positive feelings, self esteem, negative feelings and spirituality from the Psychological Domain, and pain, energy and sleep from the Physical Health Domain. Body Image (.38) from the Psychological Domain loaded marginally below the recommended factor loading. The third component again contained the three items of the Social Domain plus the recreation item from the Environment Domain. Together these accounted for 9% of the variance. The fourth and final component contained three items from the Physical Health Domain, which together accounted for 8% of the variance. One remaining item from the Psychological Domain: cognitions (.38) loaded to this component below the recommended factor loading criterion. Although there were some similarities with the WHOQOL-BREF domains, the overall fit was marginal, indicating

a different structure for WHOQOL Importance and failing to support the *a priori* hypothesis of a four domain structure.

Table 6.8 Rotated fixed factor loadings of the WHOQOL Importance items

<i>N</i> = 152	Component			
WHOQOL Importance Facet	1	2	3	4
Home environment	.699			
Finances	.677			
Safety	.607			
Health care	.605			
Transport	.600			
Physical environment	.579			
Mobility	.484			
Positive feelings		.724		
Self Esteem		.719		
Negative feelings		.634		
Pain		.640		
Energy		.536		
Sleep		.481		
Spirituality		.404		
Relationships			.788	
Support			.695	
Sex			.547	
Recreation			.538	
Activities				.694
Work				.651
Medication				.560
Initial Eigenvalues	6.25	1.92	1.55	1.42
Rotated % of variance	14.65	14.17	9.42	8.19

6.3.3.3 GOSS-Q

Exploratory PCA was also conducted on the items of the GOSS-Q. The Kaiser-Meyer-Olkin score (.86) indicated that sampling adequacy was good and Bartlett's test of Sphericity confirmed that factor analysis was appropriate ($\chi^2 (df = 15) = 462.59 p < .001$). However, the PCA yielded only one component with an eigenvalue > 1 . This explained a total of 58% of the variance. The scree plot confirmed this single component model. As only one component was extracted, rotated component loadings were not calculated thus the unrotated loadings are given in Table 6.9. However, within this data were 12 residuals (80%) that were greater than .05, suggesting that the differences between the observed correlation coefficients and the ones predicted by the model were large. This suggests the model yielded by the PCA was unstable, which may be a result of the small number of items within the scale.

Table 6.9 Unrotated factor loadings of the items of the GOSS-Q

<i>N</i> = 191	Component
GOSS-Q Facet	1
Social	.827
Independence	.817
Psychological	.792
Environmental	.778
Physical	.752
Spiritual	.593
Initial Eigenvalue	3.50
% of variance	58.32

6.3.4 Discriminative validity of the WHOQOL-BREF and WHQOL Importance instruments

The discriminative validity of the WHOQOL instruments was investigated to determine if these measures distinguished between participants of different levels of physical health.

6.3.4.1 *Discriminative validity of the WHOQOL-BREF for health status groups identified by WHOQOL-BREF overall health ratings*

Firstly the ability of the WHOQOL instruments to discriminate between participants in different categories of health status was tested in relation their responses to the overall health question of the WHOQOL-BREF. In this question, responses ranged from “very dissatisfied” to “very satisfied”. Prior to analysis, the scores of the overall health facet of the WHOQOL-BREF were re-coded into four health status groups indicative of dissatisfied, neither/nor, satisfied and very satisfied. This was done as only very few participants ($N = 5$) had responded an original additional category of “very dissatisfied”. Recoding resulted in “dissatisfied” group size of $N = 44$), which produced a more even balance of health status group numbers. One-way ANOVAs were applied to find out if there were differences between these groups in terms of WHOQOL-BREF and WHOQOL Importance domain scores. As seen in Table 6.10, the mean scores of each WHOQOL-BREF domain were lowest for the dissatisfied group, higher for the neither satisfied nor dissatisfied group, higher again for the satisfied group and highest for the very satisfied group. The one-way ANOVAs showed significant differences between the groups for all domains (Physical Health: *Welch's* $F(3,84.68) = 70.88, p < .001$; Psychological Health: *Welch's* $F(3,76.49) = 20.08, p < .001$; Social: *Welch's* $F(3,71.33) = 8.81, p < .001$; Environment: $F(3,182) = 17.73, p < .001$) showing that the WHOQOL-BREF had good discriminative validity overall.

Post-hoc Games-Howell test results for the WHOQOL-BREF domains (Table 6.11) revealed significant differences in the Physical Health domain between all health status groups (dissatisfied $M = 48.2$; neither/nor $M = 63.8$; satisfied $M = 76.32$; and very satisfied $M = 90.37$), therefore showing that Physical Health domain scores were different between participants in each health status category. In the Psychological Health domain, significant differences were found between most groups, the only exception being that no significant difference was found between the domain scores of the neither/nor and satisfied groups (neither/nor $M = 62.61$; satisfied $M = 68.70$), suggesting similarity in the scores of participants in these two health status categories. Significant differences in Social domain mean scores were found for all groups except dissatisfied and neither/nor, and satisfied and very satisfied. The results indicated similarity in scores at both ends of the health status scale, i.e. little differentiation between the two lowest

Table 6.10 Means, standard deviations, and analysis of variance of WHOQOL scores for health status groups, identified by the WHOQOL-BREF overall health rating, examining the discriminative validity of the WHOQOL instruments

Measure		Dissatisfied (<i>N</i> = 41 – 44)	Neither satisfied nor dissatisfied (<i>N</i> = 38 – 39)	Satisfied (<i>N</i> = 74 – 80)	Very satisfied (<i>N</i> = 20 – 24)	<i>df</i>	<i>F</i>	<i>p</i>
WHOQOL-BREF Domains								
Physical Health	Mean (<i>SD</i>)	48.28 (20.23)	63.77 (14.92)	76.32 (14.00)	90.37 (6.41)	3,84.68	70.89 ^a	.001 ^{***}
Psychological Health	Mean (<i>SD</i>)	52.99 (17.83)	62.61 (13.93)	68.70 (11.61)	77.22 (9.22)	3,76.49	20.08 ^a	.001 ^{***}
Social Relationships	Mean (<i>SD</i>)	56.16 (22.42)	62.69 (20.54)	72.55 (14.95)	75.69 (15.72)	3,71.33	8.81 ^a	.001 ^{***}
Environment	Mean (<i>SD</i>)	64.44 (15.41)	71.94 (13.52)	79.43 (12.08)	85.03 (11.51)	3,182	17.73	.001 ^{***}
WHOQOL Importance Domains								
Physical Health	Mean (<i>SD</i>)	80.57 (9.94)	75.42 (10.19)	79.67 (12.65)	86.25 (10.25)	3,168	4.11	.008 ^{**}
Psychological Health	Mean (<i>SD</i>)	76.79 (12.19)	72.54 (11.23)	76.25 (13.03)	74.21 (17.81)	3,170	0.91	.437
Social Relationships	Mean (<i>SD</i>)	71.34 (14.32)	65.13 (18.19)	69.59 (17.09)	69.84 (21.97)	3,170	0.92	.433
Environment	Mean (<i>SD</i>)	80.80 (9.52)	76.91 (11.93)	79.06 (12.62)	77.08 (12.94)	3,170	0.87	.458

^a Welch's *F*

** $p < .01$; *** $p < .001$

health status groups and between the two groups who were satisfied with their health status.

Table 6.11 Post-hoc Games-Howell test results showing the discriminative validity of the WHOQOL-BREF domains by health status, as identified by the WHOQOL-BREF overall health rating

Domain	Health status groups (N=21-80) (WHOQOL-BREF overall health)	Mean difference	Standard Error	<i>p</i>
Physical	Dissatisfied – neither nor	-15.49	3.89	.001***
	Dissatisfied – satisfied	-28.04	3.43	.001***
	Dissatisfied – very satisfied	-42.09	3.33	.001***
	Neither /nor – satisfied	-12.55	2.89	.001***
	Neither / nor – very satisfied	-26.60	2.76	.001***
	Satisfied – very satisfied	-14.05	2.07	.001***
Psychological	Dissatisfied – neither nor	-9.62	3.49	.036*
	Dissatisfied – satisfied	-15.71	2.99	.001***
	Dissatisfied – very satisfied	-24.23	3.28	.001***
	Neither /nor – satisfied	-6.09	2.59	.097
	Neither / nor – very satisfied	-14.62	2.92	.001***
	Satisfied – very satisfied	-8.53	2.30	.003**
Social	Dissatisfied – neither nor	-6.53	4.72	.512
	Dissatisfied – satisfied	-16.40	3.77	.001***
	Dissatisfied – very satisfied	-19.54	4.66	.001***
	Neither /nor – satisfied	-9.86	3.69	.047*
	Neither / nor – very satisfied	-13.01	4.59	.031*
	Satisfied – very satisfied	-3.14	3.62	.821
Environment	Dissatisfied – neither nor	-7.50	3.18	.093
	Dissatisfied – satisfied	-14.99	2.69	.001***
	Dissatisfied – very satisfied	-20.58	3.30	.001***
	Neither /nor – satisfied	-7.49	2.56	.021*
	Neither / nor – very satisfied	-13.08	3.19	.001***
	Satisfied – very satisfied	-5.60	2.71	.183

* $p < .05$; ** $p < .01$; *** $p < .001$,

A similar pattern was found in the Environment domain where the mean scores of the two lowest health status groups (dissatisfied and neither/nor) did not differ significantly and the same was true of the two highest health status groups (satisfied and very satisfied).

The results indicated that, as predicted, the WHOQOL-BREF was able to discriminate overall between each level of health status, as categorised using the overall health question of the same measure. This was also true of the Physical Health domain. However the Psychological Health domain could not discriminate between the two middle health status groups. Neither the Social nor the Environment domains were able to discriminate between consecutive groups at each end of the health status scale (the two highest health and the two lowest health groups). Unsurprisingly the Physical Health domain therefore proved to be best able to differentiate between participants according to their responses to the overall health item.

6.3.4.2 Discriminative validity of the WHOQOL Importance for health status groups identified by WHOQOL-BREF overall health ratings

Table 6.12 Post-hoc Games-Howell test results examining the discriminative validity of the WHOQOL Importance Physical Health domain by health status, as identified by the WHOQOL-BREF overall health rating

Domain	Health status groups (N=21-80) (WHOQOL-BREF overall health)	Mean difference	Standard Error	<i>p</i>
Physical	Dissatisfied – neither nor	5.16	2.28	.118
	Dissatisfied – satisfied	0.91	2.14	.974
	Dissatisfied – very satisfied	-5.68	2.77	.189
	Neither /nor – satisfied	-4.25	2.23	.233
	Neither / nor – very satisfied	-10.83	2.84	.003**
	Satisfied – very satisfied	-6.58	2.72	.092

** $p < .01$

As shown in Table 6.10 earlier, a one-way ANOVA revealed a significant between groups effect in the WHOQOL Importance Physical Health domain ($F(3,168) = 4.11$, p

< .01). Post-hoc analysis suggested a significant difference in this domain only between the neither/nor group and the very satisfied group (see Table 6.12). No effect was found for the other three domains indicating that the Importance scale had little ability to discriminate between health status groups as categorised by responses the overall health item of the WHOQOL-BREF.

6.3.4.3 Discriminative validity of the WHOQOL-BREF for health status *identified by EQ-5D VAS ratings*

The discriminative validity of the WHOQOL instruments was tested in a second analysis in relation to health status as measured by the EQ-5D VAS, on which scores range from 0 – 100 where 0 is the worst possible health and 100 the best possible health. Scores on the VAS were re-coded into groups of poorest, poor, moderately good, and best health according to the 25th, 50th & 75th percentiles of the data. The original score distribution and the recoded group distribution is given in Table 6.13. It was noticeable that a clustering effect was present around the deciles, and to a lesser degree, the 5 points either side. This effect has been previously identified and postulated to result from the inclusion of incremental markers on the scale (Harrison, Boonen, Tugwell, & Symmons, 2009).

As can be seen in Table 6.14, the mean scores of the WHOQOL-BREF Physical Health, Psychological Health and Environment domains rose incrementally with increasing health status groups. Overall, the one-way ANOVAs showed F to be significant between the groups for all domains *Welch's* $F(3,93.9) = 36.33, p < .001$; Psychological Health: *Welch's* $F(3,94.84) = 19.63, p < .001$; Social: $F(3,173) = 10.00, p < .001$; Environment: *Welch's* $F(3,94.67) = 12.03, p < .001$). It was however noted that, for the Social Domain, the moderately good health status group had a lower mean EQ-5D VAS score than the poor health status group.

All post-hoc Games-Howell test results for the WHOQOL-BREF domains are given in Table 6.15. Results showed significant differences in the Physical Health domain between all groups except between the moderately good health and best health groups, suggesting WHOQOL-BREF domain scores did not correspond to these EQ-5D VAS groups.

Table 6.13 Frequency of EQ-5D VAS scores

EQ-5D VAS score	Original		Grouped		Health
	<i>N</i>	%	<i>N</i>	%	
20	1	.5	50	26.5	Poorest
25	2	1.1			
30	4	2.1			
35	3	1.6			
40	8	4.2			
43	1	.5			
45	1	.5			
50	12	6.3			
55	3	1.6			
57	1	.5			
60	5	2.6	45	23.8	Poor
65	9	4.8			
67	1	.5			
69	1	.5			
70	28	14.8			
75	15	7.9	48	25.4	Moderately good
76	2	1.1			
78	1	.5			
80	23	12.2			
81	1	.5			
84	1	.5	46	24.3	Best
85	18	9.5			
87	2	1.1			
88	2	1.1			
89	1	.5			
90	23	12.2			
92	2	1.1			
95	11	5.8			
96	1	.5			
97	2	1.1			
98	2	1.1			
100	2	1.1			
Total	189	100.0		100.0	

Table 6.14 Means, standard deviations, and analysis of variance of WHOQOL scores for health status groups, identified by the EQ-5D VAS, examining the discriminative validity of the WHOQOL instruments

Measure		Poorest health (<i>N</i> = 47 – 49)	Poor health (<i>N</i> = 41 – 43)	Moderately good health (<i>N</i> = 43 – 46)	Best health (<i>N</i> = 31 – 39)	<i>df</i>	<i>F</i>	<i>p</i>
WHOQOL-BREF Domains								
Physical Health	Mean (<i>SD</i>)	48.31 (21.13)	66.46 (14.28)	77.86 (12.48)	83.08 (11.50)	3,93.90	36.33 ^a	.001***
Psychological Health	Mean (<i>SD</i>)	53.89 (17.67)	64.50 (12.76)	66.94 (13.22)	75.44 (9.18)	3,94.84	19.63 ^a	.001***
Social Relationships	Mean (<i>SD</i>)	56.78 (21.82)	69.67 (17.09)	65.58 (17.71)	78.21 (16.84)	3,173	10.00	.001***
Environment	Mean (<i>SD</i>)	64.34 (17.21)	75.15 (11.20)	77.74 (11.25)	82.57 (11.27)	3,94.67	12.03 ^a	.001***
WHOQOL Importance Domains								
Physical Health	Mean (<i>SD</i>)	79.94 (10.86)	77.47 (10.29)	80.32 (13.51)	82.95 (10.09)	3,158	1.39	.248
Psychological Health	Mean (<i>SD</i>)	75.09 (12.11)	75.57 (13.32)	76.43 (12.01)	76.61 (15.05)	3,160	0.13	.944
Social Relationships	Mean (<i>SD</i>)	72.40 (13.55)	67.99 (16.89)	67.80 (18.20)	73.92 (17.45)	3,160	1.37	.255
Environment	Mean (<i>SD</i>)	79.00 (10.90)	79.04 (11.72)	78.20 (11.93)	81.57 (12.94)	3,160	0.53	.664

^a Welch's *F*

p < .001

Table 6.15 Post-hoc Games-Howell test results examining the discriminative validity of the WHOQOL-BREF domains by health status, as identified by the EQ-5D VAS

Domain	Health status groups (N=38-49) (EQ-5D VAS)	Mean difference	Standard Error	<i>p</i>
Physical	Poorest health – poor health	-18.15	3.75	.001***
	Poorest health – moderately good health	-29.54	3.57	.001***
	Poorest health – best health	-34.77	3.57	.001***
	Poor health – moderately good health	-11.40	2.86	.001***
	Poor health – best health	-16.62	2.87	.001***
	Moderately good health – best health	-5.23	2.63	.203
Psychological	Poorest health – Poor health	-10.60	3.19	.007**
	Poorest health – moderately good health	-13.05	3.20	.001***
	Poorest health – best health	-21.55	2.93	.001***
	Poor health – moderately good health	-2.45	2.77	.813
	Poor health – best health	-10.94	2.45	.001***
	Moderately good health – best health	-8.49	2.47	.005**
Social	Poorest health – Poor health	-12.89	4.06	.011*
	Poorest health – moderately good health	-8.80	4.07	.141
	Poorest health – best health	-21.42	4.12	.001***
	Poor health – moderately good health	4.09	3.69	.685
	Poor health – best health	-8.53	3.75	.113
	Moderately good health – best health	-12.63	3.75	.006**
Environment	Poorest health – Poor health	-10.80	2.99	.003**
	Poorest health – moderately good health	-13.40	2.97	.001***
	Poorest health – best health	-18.22	3.06	.001***
	Poor health – moderately good health	-2.59	2.38	.697
	Poor health – best health	-7.42	2.50	.021*
	Moderately good health – best health	-4.83	2.47	.214

* $p < .05$, ** $p < .01$, *** $p < .001$,

In the Psychological Health domain, significant between groups differences were also found for all groups with the exception of poor health and moderately good health, indicating these groups had similar mean WHOQOL-BREF Psychological Health domain scores.

Significant differences in Social domain mean scores were found between the poorest and best health groups, between the poorest and poor health groups and between the moderately good and best health groups. However the moderately good health group mean was not significantly different from either the poorest or poor health groups. As highlighted earlier, the mean Social domain QoL score of the moderately good health group was lower than that of the poor health group and these results also suggest that the relative health identified in the EQ-5D groups was not consistent with the Social domain QoL scores.

In the Environment domain, once again the poorest health group mean significantly differed from that of the poor health group and from both the moderately good and best health groups. However, there was no significant difference found between either the poor health and moderately good health groups, nor between the moderately good and best health groups, indicating similarity in the mean WHOQOL-BREF Environment scores of the sample, when grouped by their respective EQ-5D VAS scores.

In summary the results indicated that the overall WHOQOL-BREF was able to discriminate between each level of health status, as categorised using the the EQ-5D VAS. This was also true of the Physical Health domain except for the two highest health status groups – moderately good and best health. However the Psychological Health domain did not discriminate between the poor and the moderately good health status groups. The Social domain also lacked discriminative validity in terms of EQ-5D VAS scores, except for consecutive groups at the ends of the scale (poorest and poor health; moderately good and best health) and between either end of the scale: the poorest and best health groups. The Environment domain also lacked discriminative validity between the consecutive groups: poor and moderately good health and between the moderately good and best health groups. At the domain level therefore the discriminative validity of the WHOQOL-BREF was better for physical health scores in relation to the EQ-5D VAS than for scores in the Psychological Health, Social or Environment domains.

6.3.4.4 Discriminative validity of the WHOQOL *Importance* for health status identified by EQ-5D VAS ratings

The mean scores of the WHOQOL Importance were given in Table 6.14 earlier. As was also shown, one-way ANOVAs revealed F not to be significant for any of the four domains, indicating no ability of the WHOQOL Importance to discriminate between groups in relation to health scores derived from the EQ-5D VAS. While the findings had supported the original predictions of the good discriminative validity of the WHOQOL-BREF against categories of health status, the WHOQOL Importance did not demonstrate the same ability.

6.3.5 Convergent and concurrent validity of the WHOQOL-BREF, WHOQOL Importance, GOSS-Q and EQ-5D VAS

Correlations between the measures were calculated to see whether the domains within the WHOQOL-BREF and WHOQOL Importance were significantly related to each other, as well as to determine whether these instruments and the EQ-5D VAS and GOSS-Q scales were independent. As discussed in section 6.1.1, in assessing convergent validity, it had been expected that the WHOQOL-BREF domains would demonstrate moderate correlations with one another, as all are intended to measure related, but independent, constructs within the definition of QoL. It was predicted that the same would be true of the WHOQOL Importance. Measuring the same, subjective views on Physical Health, the EQ-5D VAS and WHOQOL-BREF Physical Health Domain had been predicted to be correlated with one another. It was also expected that a relationship would be found between the WHOQOL-BREF domains and the GOSS-Q domains, as questions in the latter had been written specifically to reflect WHOQOL-100 domains of QoL. Findings are presented in Table 6.16.

6.3.5.1 Convergent validity - correlations within the instruments

As predicted, the correlations between the domains of the WHOQOL-BREF were all found to be significant and mostly moderate, ranging from $r = .50$ to $r = .67$. The only exception was the weak correlation found between the Physical Health and Social domains, indicating that these domains were more independent of one another.

Table 6.16 Correlations within and between the WHOQOL-BREF, WHOQOL Importance, GOSS-Q and EQ-5D VAS

		WHOQOL-BREF				WHOQOL Importance				GOSS-Q				ED-5D VAS		
Instrument & domain		Physical	Psychological	Social	Environment	Physical	Psychological	Social	Environment	Physical	Psychological	Social	Environ-mental	Independence	Spiritual	
WHOQOL-BREF	Physical	1	.613**	.334**	.626**	.131	-.042	-.096	-.094	.465**	.428**	.349**	.386**	.438**	.264**	.715**
	Psychological		1	.544**	.666**	-.024	-.073	-.049	.001	.254**	.367**	.360**	.287**	.187*	.193*	.526**
	Social			1	.500**	.004	.010	.076	.074	.149*	.377**	.416**	.215**	.125	.160*	.342**
	Environment				1	-.041	-.013	-.089	-.006	.294**	.418**	.434**	.412**	.316**	.196**	.523**
WHOQOL Importance	Physical					1	.574**	.383**	.523**	.174*	.025	-.048	-.014	.129	.088	.109
	Psychological						1	.463**	.575**	.127	.125	.096	.022	.147	.278**	.082
	Social							1	.373**	.144	.143	.174*	.054	.067	.077	-.017
	Environment								1	.015	-.042	-.033	-.081	-.014	.092	.031
GOSS-Q	Physical									1	.457**	.516**	.530**	.607**	.307**	.417**
	Psychological										1	.630**	.538**	.509**	.473**	.357**
	Social											1	.588**	.595**	.399**	.416**
	Environmental												1	.584**	.280**	.265**
	Independence													1	.398**	.370**
	Spiritual														1	.204**

* Significant at $p < .05$; ** Significant at $p < .01$

Within the WHOQOL Importance instruments, again all domains correlated significantly with one another, supporting the *a priori* hypothesis. The majority of correlations were of moderate strength, ranging from $r = .46$ to $r = .58$. Two exceptions which showed weak correlations were between the Physical Health and Social domains (commensurate with the correlations within the WHOQOL-BREF) and between the Social and Environment domains. This suggested that the Social Domain was relatively independent of these other constructs.

The domains within the GOSS-Q were also significantly associated with one-another with most correlations being of moderate strength (ranging from $r = .46$ to $r = .63$). Lower correlations were found between the Spiritual and other domains. Although still significant, these associations were lower in terms of strength of relationship and ranged from $r = .28$ to $r = .47$. As such, the Spiritual construct could be considered more independent than other domains within the overall concept of QoL-related goal orientation.

6.3.5.2 Concurrent validity - correlations between the instruments

All correlations are again shown in Table 6.16. The domains of the WHOQOL-BREF were found to have no relationship with those of the WHOQOL Importance instrument, indicating independence between the two, (i.e. that they measure different constructs).

As had been predicted the WHOQOL-BREF correlated with the EQ-5D VAS, and the strongest correlation was between the latter and the Physical Health Domain of the WHOQOL-BREF ($r = .72$). A biserial correlation analysis between EQ-5D VAS and the “currently ill or healthy?” question which accompanied the WHOQOL-BREF also suggested a strong relationship between the two variables ($r = .54, p < .001$; $y^\dagger = .31, r_b = .74$). The EQ-5D VAS also demonstrated a moderate correlation with the Psychological Health and Environment domains of the WHOQOL-BREF, and a weak correlation with the Social Domain. Overall, these results suggested an association between the two measures, but especially in terms of physical health.

Correlations between the WHOQOL-BREF and GOSS-Q domains were mixed although all except one was significant. Moderate associations were found between the Physical

Health Domain of the WHOQOL-BREF and the GOSS-Q's Physical, Independence and Psychological domains. Similar moderate correlations were found between the Environment Domain of the WHOQOL-BREF and the GOSS-Q's Social, Psychological and Environment domains. The WHOQOL-BREF Social Domain was also moderately correlated with the Social Domain of the GOSS-Q. These findings only partially supported the prediction of association between the two measures.

The WHOQOL Importance domains were not correlated with the EQ-5D VAS and only weak correlations were found with three of the GOSS-Q domains. All domains of the GOSS-Q were found to be significantly related to the EQ-5D VAS.

6.3.6 The effects of age and gender on WHOQOL-BREF, WHOQOL Importance, GOSS-Q and EQ-5D VAS scores

6.3.6.1 WHOQOL Instruments

As measured by the WHOQOL-BREF, QoL was good for both genders. Mean scores for males ranged from 66.39 ($SD = 15.83$) for Physical Health to 73.61 ($SD = 16.10$) for the Environment domain. Similarly females rated QoL as good (ranging from Psychological Health $M = 63.94$ ($SD = 15.49$) to Environment $M = 75.94$ ($SD = 14.13$)). Both genders also rated all domains as important. Mean scores for males ranged from 66.47 ($SD = 18.82$) in the Social domain to 78.56 ($SD = 11.88$) for the Physical Health domain. Female mean scores for importance ranged from $M = 70.53$ ($SD = 16.45$) for the Social domain to $M = 80.43$ ($SD = 11.40$) for the Physical Health domain. When the sample was dichotomised into two age groups: 18-44 and 45+, results showed that both younger and older adults had good QoL (all WHOQOL-BREF mean domain scores were above 60) and that both groups also rated the domains as important, with all mean scores found to be above 65.

As shown in Table 6.17, MANOVA analysis revealed significant differences ($F(8,156) = 4.36, p < .001$) between age groups (younger: 18-44 years; older: 45 + years) with a large effect size ($\eta^2 = 0.18$). Between subjects effects showed significant age differences in the WHOQOL-BREF Psychological Health domain (younger group $M = 60.18$, ($SD = 17.05$), older group $M = 66.65$ ($SD = 14.04$), $F(1,163) = 5.83, p < .05, \eta^2 = 0.04$) indicating better psychological QoL for the older group.

Table 6.17 MANOVA analysis of between-subjects effects showing differences in WHOQOL-BREF and WHOQOL Importance domains by gender and dichotomised age.

Gender	Age	WHOQOL-BREF					WHOQOL Importance			
			Physical	Psychological	Social	Environment	Physical	Psychological	Social	Environment
Male N = 64	< 45 N=17	Mean (SD)	69.96 (18.17)	61.27 (17.04)	60.78 (19.27)	69.12 (14.90)	80.04 (9.45)	74.17 (6.92)	68.63 (17.81)	74.26 (13.05)
	45 + N=47	Mean (SD)	66.22 (22.44)	68.24 (15.14)	64.61 (19.61)	75.33 (16.50)	78.02 (12.69)	73.07 (14.07)	65.69 (19.29)	77.20 (11.88)
Female N = 103	< 45 N=39	Mean (SD)	71.99 (19.81)	59.70 (17.26)	64.32 (20.85)	73.88 (15.99)	82.42 (12.16)	77.03 (15.29)	77.14 (14.90)	77.82 (11.42)
	45 + N=64	Mean (SD)	67.49 (20.55)	65.48 (13.18)	70.83 (17.49)	77.06 (12.57)	79.32 (11.18)	76.67 (12.79)	66.67 (15.85)	81.93 (11.54)
MANOVA (<i>df</i> = 8,156)			<i>F</i>		<i>p</i>	η^2				
Gender			1.888		.065	.088				
Age			4.356		.001***	.183				
Interaction Gender * Age			0.546		.821	.027				

***Significant at $p < .001$

Significant differences were also found between age groups in the WHOQOL Importance Social Domain (younger group $M = 74.55$ ($SD = 16.16$), older group $M = 66.25$ ($SD = 17.32$), $F(1,163) = 5.20$, $p < .05$, $\eta^2 = 0.03$), indicating that the older group felt social QoL to be less important.

No main effect for gender was found. However between subjects effects showed a significant difference in the WHOQOL Importance Environment domain (male $M = 76.42$ ($SD = 12.16$), female $M = 80.37$ ($SD = 11.61$), $F(1,163) = 4.08$, $p < .05$). This suggested that females saw environmental QoL as more important than males, however the effect was small ($\eta^2 = 0.02$). There was no significant interaction between age and gender.

6.3.6.2 GOSS-Q and EQ-5D VAS

MANOVA analysis on the GOSS-Q data revealed a significant main effect of age ($F(6,176) = 3.49$, $p < .05$, $\eta^2 = 0.11$). Further independent samples t tests on the GOSS-Q domains showed significant differences for four of the six domains: Physical, Psychological, Environmental and Independence ($p \leq .008^4$) (details of the GOSS-Q scale were described earlier in Chapter 4). The mean scores for the Physical domain (younger group $M = 4.31$ ($SD = 1.23$), older group $M = 3.69$ ($SD = 1.25$)) suggested that while the younger group were moving towards their Physical QoL, the older group felt they were moving away from it. In the Psychological and Environmental domains, while the mean scores indicated that both groups were moving towards their ideal QoL, the younger group were doing so at a faster rate (Psychological domain: younger group $M = 4.75$ ($SD = 1.15$), older group $M = 4.15$ ($SD = 1.04$); Environmental domain: younger group $M = 4.78$ ($SD = 0.90$), older group $M = 4.29$ ($SD = 0.10$)). In terms of their QoL relating to Independence, while the younger group were moving towards this ($M = 4.81$ ($SD = 1.32$)) the older group remained stable ($M = 4.00$ ($SD = 1.24$)).

⁴ The usual p value of significance ($p < .05$, was adjusted using the Bonferroni correction for multiple comparisons to a significance criterion of $p < .008$).

No significant differences were found between the groups in terms of the Social or the Spiritual domains of the GOSS-Q. Neither were any significant differences found between the groups in terms of EQ-5D VAS scores. The data were also analysed by gender to identify any significant differences between the scores of males and females in terms of the EQ-5D VAS or the GOSS-Q domain but none were found.

6.4 Discussion

6.4.1 Main findings

6.4.1.1 Best quality of life and highest importance

Examination of WHOQOL instrument mean scores indicated highest QoL in relation to the Environment Domain and greatest importance for Physical Health. This suggests a high level of satisfaction with those aspects of QoL relating to the community in which participants live, their housing arrangements, the local infrastructure as well as more individual context such as their financial situation or their recreational and leisure activities. This may be a reflection on the particular sample in this study. For example, almost half the sample (47) lived in a suburban environment, and just over a third (35%) in a rural setting. Moreover 49% reported their financial situation as above average and only 24% as below average. The importance of physical health may also have been related to the particular sample as 70% reported having a chronic illness. This may also help to explain the finding that mean scores in the GOSS-Q indicated movement towards ideal QoL states for all domains except physical health.

6.4.1.2 Psychometric properties of the measures

Internal consistency

Cronbach's α was good for three of the four WHOQOL-BREF domains: Physical Health, Psychological Health, and Environment. The lower α value in the Social Relationships domain is consistent with previous findings, where typically it has been found to be in the region of .64 - .69 (Kalfoss et al., 2008; Skevington, Lotfy, et al., 2004; W. Taylor et al., 2004; The WHOQOL Group, 1998a; Van Esch et al., 2011). As the Social Domain calculation is based on only three items, compared to six to eight

items in the other domains, lower α values might be expected due to the sensitivity to numbers of the statistic (Skevington, Lotfy, et al., 2004).

Commensurate with previous research Cronbach's α for the WHOQOL Importance scale was also found to be acceptable (Molzahn et al., 2011; Molzahn et al., 2010). The internal consistency of the GOSS-Q was acceptable and consistent with that of the original GOSS scale (Yardley & Dibb, 2007).

Construct validity

Construct validity was assessed using FA and exploratory PCA. As discussed in Chapter 3, the WHOQOL-BREF four domain model was based on a reorganisation of the six theoretical domains of the WHOQOL-100. Facets of the latter that related to independence and spirituality were included in the WHOQOL-BREF within the Physical Health and Psychological Health domains respectively (Skevington, Lotfy, et al., 2004). Exploratory FA of the present WHOQOL-BREF suggested a six factor model which corresponded moderately well with the theoretical WHOQOL-BREF four domain structure but also contained an additional factor containing a mix of facets from different domains and another which presented as a "medical" factor (pain and medication facets). These findings are commensurate with those of a previous study by Skevington et al. (2004), which investigated the psychometric properties of the WHOQOL-BREF in an international field trial, and found most sites had four to six factors with eigenvalues greater than 1.0.

When the FA was repeated in the present study with four fixed factors, results revealed a model that corresponded closely to the four domain theoretical model of the WHOQOL-BREF. Each domain was reflected in one of the four factors in the model and only two items cross-loaded onto factors other than those in the hypothetical structure. In both models the Spirituality item from the Psychological Health Domain and the Home Environment item from the Environment domain were present in the same factor as the Social Domain items. This has not been found in previous studies (Kalfoss et al., 2008; Skevington, Lotfy, et al., 2004) and further investigation in future studies would be valuable in determining whether this finding was unique to this sample. Whilst these results were encouraging in confirming the construct validity of the WHOQOL-BREF, it

must be borne in mind that, although acceptable for FA, the sample size was modest and the solutions may therefore not be stable.

The results of the PCA on the WHOQOL Importance data suggested a seven component model. The first three mapped broadly onto the Environment, Psychological Health and Social Domains of the WHOQOL-BREF suggesting a structure similar to that of the its four domain model. However sleep was a single item component and the remaining components contained a mix of facets from the Physical Health, Psychological Health and Environment Domains. A more similar structure to the WHOQOL-BREF was found when the model was fixed at four factors, although again there was mixing of items from different domains in three of the four components. This is the first study to examine the construct validity of the WHOQOL Importance in relation to the original WHOQOL-BREF 4-domain model and results are mixed, suggesting some correspondence but also some differences, particularly in the exploratory model. It is plausible that Importance of QoL is conceptualised as in independent construct from subjective judgements of QoL and thus an identical model would not be demonstrated. Correlations between the WHOQOL-BREF and WHOQOL Importance facets will be discussed later in this chapter to explore this assertion further.

When PCA was applied to the six domains of the GOSS-Q, they loaded to a single factor suggesting the scale measured the single construct of QoL-related goal orientation. However, the PCA model was not robust, which may be due to the small number of items in the scale, and this conclusion is therefore necessarily tentative.

Discriminative validity

Good discriminative validity was demonstrated for all domains of the WHOQOL-BREF in relation to health status groups as derived from the overall health item. This is consistent with previous studies where similar results have been found when investigating the differences between ill and well people (Skevington, Lotfy, et al., 2004; Skevington & McCrate, 2012; The WHOQOL Group, 1998a) As predicted, the Physical Health Domain was demonstrated to best discriminate between each of the different health status groups.

The WHOQOL Importance instrument did not discriminate between health status groups for any domain except Physical Health and in this case it only did so between the “neither satisfied nor dissatisfied” and the “very satisfied” health status groups. These findings again suggest that individuals’ subjective judgements of the importance of aspects of QoL may be independent from their subjective judgements of QoL itself. Contradictory evidence was found in a previous study where mean importance ratings were generally higher for healthy participants (Molzahn et al., 2010). However the statistical significance of the variance between the groups in that study was not published. In addition, Molzahn’s (2010) data were taken from an international investigation of older adults and thus reflects a different population from that used in the present study.

The WHOQOL-BREF was also found to have discriminative validity in relation to health status, when the latter was derived from EQ-5D VAS scores. This provided a more rigorous validation of the WHOQOL-BREF, as the health status measure used to categorise the data was from an independent source. As before, the ability of the Physical Health Domain to discriminate was superior to the other domains although it was not able to discriminate between the two highest health-status groups, suggesting a similarity in Physical Health domain scores for participants at the upper end of the health status scale. The correspondence between the EQ-5D VAS and the Physical Health Domain of the WHOQOL-BREF will be discussed later. Once more the WHOQOL Importance instrument did not discriminate between the health status groups, supporting the suggestion that conceptualisations of importance may be unconnected with subjective ratings of QoL. While it might seem intuitive to the observer that health status and its importance go hand-in-hand, these results suggest a more complex relationship that is worthy of further research in the future to find out how these constructs are (or are not) related.

Associations within and between instruments

Correlations between the domains of the WHOQOL-BREF were highly significant and mostly moderate in size, as might be expected of a psychometrically robust instrument which measures different facets of QoL. As pointed out by Streiner and Norman (2008), scores measuring the same construct should be related, although too high a correlation would indicate that they are actually measuring the same thing. The data suggested least

association between the Physical Health and Social Domains and greatest association between the Psychological Health and Environment Domains, both of which confirm previous findings (Ackerman et al., 2006; Kalfoss et al., 2008). Correlations between the domains of the WHOQOL Importance suggested highly significant relationships between all the domains, although again the Social Domain correlated less strongly with the Physical Health and Environment Domains. As no other studies have published data on correlations between the four WHOQOL Importance domains, comparisons could not be made. However, the data here again indicated the relative independence of the Social Domain and its relative weakness as a construct within the WHOQOL model.

Correlations between the domains within the GOSS-Q were also found to be highly significant and mostly moderate. As suggested earlier in section 6.3.3.3, and also earlier in this section, this association between the domains suggested a coherent model of QoL-related goal orientation. However, none were too highly correlated, which would have suggested an overlap of the domain constructs.

Convergent validity between the measures was also assessed. Interestingly, the WHOQOL-BREF and WHOQOL Importance domains were not found to be statistically associated, suggesting they may assess different perspectives on QoL and that they may do so in relatively independent ways. A previous study by Skevington and O'Connell (2004) had found significant, but very small, correlations for 18 of 24 facets and pointed out that this lack of association was noteworthy, given their large international sample of over 4,000 participants. Whilst both measures were derived from a common QoL stem, Skevington and O'Connell concluded that a substantial association would not necessarily have been theorised from the WHOQOL Group's definition of QoL and that the information provided by the two types of questionnaire is dissimilar. A further consideration is that, while the WHOQOL-BREF asks participants to think about their QoL over the prior two weeks, the Importance instrument has no timescale instruction as importance is considered to be a more stable construct. This temporal difference may also go some way to explaining the lack of association between the WHOQOL Importance and the WHOQOL-BREF as well as between the WHOQOL Importance and the EQ-5D, which asks participants to report their health status "today".

The WHOQOL-BREF domains and the GOSS-Q domains were found to be mostly significantly correlated, although with mixed levels of association. These significant associations were not surprising given that the GOSS-Q represented an adaptation of the original instrument that was specifically designed to mirror the WHOQOL-100 six domain model of QoL and asked participants to rate their movement towards or away from *ideal QoL* states. As such, associations were expected despite the fact that they were ostensibly measuring different constructs: one QoL, the other QoL-related goal orientation.

Correlations between the WHOQOL-BREF domains and the EQ-5D VAS showed support for the hypothesis that these would be associated as both are measures of health-related QoL. Previous studies have similarly found correlations between these measures and of similar strength (Günther et al., 2007; König et al., 2010). The EQ-5D VAS was also significantly associated with the “*are you currently ill?*” question that accompanies the WHOQOL-BREF, which offers support to the inclusion of that question as an overall measure of “wellness” at the point of questionnaire completion. Although no previous evidence was available, it was similarly expected and confirmed that the GOSS-Q domains would demonstrate small to moderate associations with the EQ-5D VAS, as they had with the WHOQOL-BREF.

The effects of age and gender

As measured by the WHOQOL-BREF, QoL was good for both genders across age groups in the present study, although psychological QoL was better for older adults. Older people have been previously found to report better psychological QoL, although the same has found to be to be the case for social and environmental QoL (Skevington, 1999). Social relationships were more important for younger people, commensurate with previous findings (Saxena et al., 2001). Contrary to the previous findings of Skevington and McCrate (2012) no interaction was found in the WHOQOL data between age and gender. However, the samples in the current study were not equal, being 62% female and 66% aged 45+, and this may have affected the results. Additionally, Skevington and McCrate’s study had used age-banded data, allowing for greater discrimination between age groups than between the dichotomised data employed here, which may have increased the responsiveness of their analysis.

Age related variation was more apparent in the GOSS-Q data. In particular, the younger group demonstrated movement towards their ideal physical QoL while the older group felt they were moving away. This is not a remarkable conclusion given the customary deterioration in physical health throughout the life course. Where both age groups felt they were moving towards their ideal state with respect to their psychological and environmental QoL, the younger group reported more rapid movement, which might be suggestive of a more general sense of progression towards life goals in the younger group. However this is a tentative assertion and further research on goal-related movement across the lifespan would be helpful in testing this speculation.

6.4.2 Study limitations and research implications

As mentioned earlier, a convenience sample was used in this study, integrating data from three prior studies. Recruiting from community sources enabled heterogeneity within the sample, but the overall numbers were small. Sample size was considered adequate for the analyses conducted, but must be acknowledged as modest, which may have implications for the stability of the findings.

Furthermore, all participants responded to invitations to take part and the impact of this self-selection bias cannot be known. It is plausible that those who chose to take part may have had a prior interest in QoL or had considered this before, and this may have affected their QoL self-judgements. The predominance of people who had a chronic illness may have similar implications in term of their QoL priorities or QoL- related goal orientation.

The psychometric properties of the WHOQOL-BREF and the EQ-5D VAS have been soundly established in previous work. However, as pointed out above, few studies have used the WHOQOL Importance instrument thus less evidence is available regarding its reliability and validity. Similarly only two studies have used the GOSS measure and consequently no validation data were available. Consequently any conclusions drawn in relation to the WHOQOL Importance and GOSS-Q can only be considered tentative and will benefit from further testing with other samples. It would also be helpful to establish the test-retest reliability of these measures. Although test-retest data were available from Study 3 in the present programme of research, all retest data followed a deliberate

manipulation and additional work with a control group comparator would add value in contributing to the literature.

CHAPTER 7. STUDY 4: FOLLOW-UP INTERVIEWS WITH A SAMPLE OF STUDY 3 PARTICIPANTS

7.1 Introduction

Following the three earlier, primarily quantitative studies, Study 4 was designed to use mixed methods to further investigate post-study reflections on the process of feeding back QoL self-judgements. The study sought overall to identify the thoughts and perceptions that participants had subsequent to receiving feedback. Within this main aim, a second objective was to relate participants' comments to components of the SRT model, including identifying any actions they had taken as a result of participating in the study. It was intended that this would test whether the SRT framework could be applied to the data. Finally the study aimed to extract insights into how the feedback intervention could be effectively applied in healthcare settings to inform its future development.

SRT (Carver & Scheier, 1982, 1998) was discussed in Chapter 2, and the different components of the negative feedback loop were elaborated. These components will be discussed in this chapter in terms of emerging evidence for each element, as contained in individuals' reflections and thoughts relating to the process of QoL feedback. Within SRT, optimism has been asserted to have important consequences on behaviours and QoL (Rasmussen et al., 2006; Scheier, 1985; Wrosch & Scheier, 2003). In a study of cancer patients, optimism was found to be positively associated with increases in both physical health behaviour e.g. eating a healthy diet and engaging in physical exercise, and psychosocial behaviours e.g. reflecting on priorities in life; spending time with family and friends; taking part in charitable or volunteer activities and spending time in religious or spiritual activities (Harper et al., 2007). Based on this evidence, it was felt that those participants in Study 3 who had been optimistic about the future effects of the QoL feedback they had received, might be most likely to have spontaneously made changes after the study had concluded. Similarly it was postulated that those who had not thought the QoL feedback would be helpful would not have made any efforts to change.

That patient-physician communication can affect patient outcomes has been known for some time (S. H. Kaplan, Greenfield, & Ware, 1989; Stewart, 1995). The information given by health professions has also been found to be associated with subjective ratings of QoL. For example, a study of breast cancer patients found that those who rated the amount of information they received as high were less depressed after and reported higher QoL than those who rated it as moderate or low (Vogel, Leonhart, & Helmes, 2009). More recently, the growing interest in QoL assessment at the level of the individual has been reflected in studies of person-centred communication regarding different aspects of QoL. It has been asserted that patients want to discuss aspects of QoL with healthcare professionals (Detmar et al., 2002; Jacobs, van de Lisdonk, Smeele, van Weel, & Grol, 2001) and that they want their health professional to be aware of how their illness affects their QoL (Detmar et al., 2000). Based on this evidence, and to gain insight into potential future applications of the feedback intervention, the present study also aimed to test this supposition.

Qualitative techniques are not designed to test causal relationships, but can be helpful in understanding individual's views and in placing quantitative findings in meaningful social contexts (Bowling, 2009). These techniques include focus groups, interviews, case and observational studies and each can be carried out in structured or unstructured ways. A semi-structured approach, preparing questions beforehand, but encouraging elaboration and discussion of topics as they arose has been argued to be key to obtaining rich data (Erlandson, Harris, Skipper, & Allen, 1993). Thereafter analysing the content of documents or narratives can combine the qualitative extraction of data with more quantitative analysis techniques, blurring the boundaries between each but creating breadth in the results. Mixing methods in this way has become a popular approach particularly in health services research (Bowling, 2009; Bowling & Ebrahim, 2005). Rather than taking a "grounded theory" approach (where concepts and theories emerge from the data) framework techniques of data analysis have been deemed appropriate in health research, involving the identification, abstraction, and charting of themes within *a priori* categories (Fayers & Hays, 2005). Based on this guidance, it was decided that semi-structured interviews, with qualitative framework analysis to elicit both quantitative and quantitative data, would best meet the aims of the present study.

The recruitment strategy for Study 4 was intended to elicit data specifically from those participants who had stated that they thought they would find their experiences of taking part in the earlier study to be helpful. It was assumed that these individuals were more likely to have reflected on taking part, or that they may have spontaneously taken some form of action as a result. This strategy was designed to seek indications of how to capitalise on the positive effects of the feedback found in the present studies, in order to inform future applications. There was no intention to investigate how QoL feedback could be applied to those individuals for whom it had previously been ineffective.

7.1.1 Research question

The research question for Study 4 was: “After receiving feedback on their self-judgements of QoL, what reflections do individuals have in relation to QoL and the processes of feedback they experienced?” Reflections in this sense related both to thoughts about QoL and to perceptions of consequences and/or actions participants identified or took as a result of receiving the feedback intervention in Study 3.

In the introduction to Study 3 (Chapter 5), the paucity of studies of the effect of giving QoL feedback to individuals was discussed and the absence highlighted of studies combining both QoL core and Importance ratings into the feedback. Furthermore, no prior evidence was available regarding spontaneous thoughts or actions that individuals may have after receiving individualised QoL feedback. As such predictions were not made about whether or not participants would look at their graphical summary profiles again. Neither could it be expected that they would reflect back on their QoL without further prompting, or that they would choose to share their graphical summary profiles with another person. In this context, a qualitative investigation into the longer term consequences of receiving this type of feedback intervention was necessarily exploratory.

7.2 Method

7.2.1 Study design

The study again employed a concurrent nested mixed methods strategy (Bowling & Ebrahim, 2005) using a semi-structured interview format. In this format quantitative data

were collected in the form of frequency distributions of responses to specific questions. Subjective reflections were elicited by the use of prompts during the interviews, within the pre-defined interview structure. Qualitative comments were explored using thematic analysis according to a pre-defined framework (which will be discussed below). A supplementary exploratory quantitative investigation using data from the Study 4 participants and a comparator group selected from Study 3 was also included.

7.2.2 Sample inclusion & exclusion

Following Study 3, participants recruited via the local GP had been specifically asked whether they would agree to take part in further research related to QoL. It was anticipated that these participants would have more recent recollections than other participants recruited in phase 1 of Study 3, some of whom had taken part over 12 months previously. Furthermore, the Ethical Approval obtained from the local NHS Research Ethics Committee included provision to re-approach the phase 2 participants. Ethical approval for re-approaching participants had not been sought in phase 1 of recruitment. Forty-one participants indicated their agreement to further involvement. Of these, 21 had also previously indicated that they thought taking part would be helpful in at one or more of the suggested time points (short, medium or long term). Wishing to investigate their positive evaluations, these 21 formed the population from which participants were selected for Study 4.

7.2.3 Recruitment

A quota sampling strategy was employed in order to reflect a sample consistent with that of the previous study i.e. 70% chronically ill, 30% healthy, and also a sample which reflected a heterogeneous mix of illness types. Heterogeneity of age groups was also an aim within the sampling strategy, although the population from which participants were drawn was primarily composed of adults aged over 45 (only 1 participant was younger than this). From the 21 suitable volunteers, thirteen Study 4 participants were subsequently selected and recruited.

Ethical approval for the study had been granted by the University of Bath, Department of Psychology Research Ethics Committee, and by the NHS South West 5 Research

Ethics Committee as part of Study 3 (Chapter 5). All participants had given written consent upon recruitment into that study. Upon recruitment into Study 4, all participants were again assured of the confidential handling of any information supplied and were asked to give their verbal consent to the written recording of their question responses and to the audio-taping of the conversation.

7.2.4 Procedure

Participants were contacted by telephone and asked if they would agree to take part in an interview about QoL and their experience of the previous study. Appointments were agreed for a telephone interview to take place at a date and time of their choosing. The interviews all followed a pre-defined schedule (see section 7.2.5). Additional prompts were used where necessary e.g. “Why?” “Why not?” “What did you conclude?”. Some conversation or explanation of points also took place as they occurred. Each participant was thanked at the end for his/her involvement in the study.

7.2.5 Measures

The interview schedule is given in Appendix Z. The questions asked were selected firstly in order to elicit accounts of what actions, if any, participants had spontaneously taken after receiving the feedback intervention. Within this, defined outcomes were: the length of time participants had looked at their graphical summary profiles again, or thought about their QoL after their participation in the prior study had concluded; whether they had shown the graphical summary profiles to or discussed the contents with anyone else, and if so who with; and any actions they had taken as a result of participating in the study. Secondly, further questions sought to examine whether additional components or instructions in to the feedback process might support a longer term effect. Participants were asked who they might consider sharing the QoL information with and what could have been provided that might have helped them better use the information. To investigate the potential application of QoL feedback in healthcare settings questions were also asked about whether participants believed QoL information would be useful to share with a health profession and, if so, what they would want the health professional to do with the information. Finally participants were asked if they felt health professionals should be more aware of QoL. Qualitative data

were collected from the responses of participants to each of the questions asked and from any of their additional comments.

7.2.6 *Data Analysis*

The audio-tapes of the interviews were transcribed verbatim and copied into NVivo, version 9. NVivo is software that enables data from interviews, focus groups or audio to be stored, organised and analysed. Each transcript was coded as follows: 1) by responses to each question; 2) by evidence relating to each component of the SRT feedback loop; 3) by pragmatic considerations, such as any value participants found from receiving feedback, suggestions for future applications, and comments on the graphical summary profiles; and 4) QoL themes derived from the WHOQOL-BREF model. Where relevant questions responses were also categorical e.g. Q: How long did you spend looking at the graphs? A: 5 minutes or less / 5 – 10 minutes / more than 10 minutes, frequencies within each category were noted.

As all participants in the Study 4 sample had previously reported their belief that the feedback would be helpful, a supplementary analysis also investigated whether their WHOQOL-BREF scores in Study 3 had differed from the scores of those others in Study 3 who had reported the feedback as unhelpful. Ten participants were identified from the Study 3 data to provide the “unhelpful” comparison group. A MANOVA analysis was applied to the Study 3 WHOQOL-BREF scores of the two samples with “helpful” and “unhelpful” as the between groups factor. The assumptions of MANOVA were checked following the guidelines of Field (2005). Variance-covariance matrices were compared using Box’s test and homogeneity of variance was confirmed by non-significance of the Levene’s test. Results were reported using Pillai’s trace, as group sizes were unequal (Field, 2005). Bonferroni corrections were applied to ensure that the cumulative Type 1 error remained below .05 throughout (Field, 2005). Assessment of effect size was calculated using J. Cohen’s (1988) guidelines for the interpretation of F and equivalent values of partial eta squared (η^2), whereby $0.01 \leq \eta^2 < 0.06$ = small; $0.06 \leq \eta^2 < 0.14$ = medium; and $\eta^2 \geq 0.14$ = large (Kinnear & Gray, 2010). Unless stated otherwise, results are reported as significant throughout this chapter where $p < .05$.

7.3 Results

The study sample was composed of 13 participants (46% male). Demographic details of the study sample are given in Table 7.1. Notably all were aged 45+. However this was commensurate with the demographic profile of the Study 3 sample recruited via the GP Practice. Interviews took between 12 and 27 minutes (median length of interview was 16 minutes) and full transcripts are given in Appendix AA.

Almost half of participants (46%) had received a college, university or postgraduate education and all described their ethnic origin as white. The majority of participants (69%) were partnered or married and the same proportion reported that they lived with their partner, spouse or family. The whole sample lived in rural or suburban community settings with none in a city or town centre. Six participants (38%) were retired with a similar proportion (39%) describing their current or prior occupation as professional or higher administrative. No participant described their income as less than average.

Of the 13 participants, 11 (85%) had been categorised in Study 3 as chronically ill with the remainder as healthy (or not having had an illness or disease of at least 12 months' duration). Using the ICD illness classification, the chronically ill sample was composed of: musculoskeletal ($N=3$); circulatory ($N=3$); respiratory ($N=1$); endocrine ($N=2$); mental and behavioural ($N=1$); and digestive ($N=1$). Eight of the participants had been in the verbal guidance experimental condition in Study 3, with the remaining 5 in the written instructions condition. (Full details of the experimental conditions were given in Chapter 5.)

Table 7.1 Demographic characteristics of Study 4 participants

			<i>N</i>	% of total (<i>N</i> =13)
Age	Males	55-64	2	15.4
		65-74	3	23.1
		75+	1	7.7
	Females	45-54	2	15.4
		55-64	1	7.7
		65-74	2	15.4
		75+	2	15.4
Education	Secondary		5	38.5
	Technical / Further Education		2	15.4
	College / University		3	23.1
	Post-graduate		3	23.1
Marital status	Single (never married)		1	7.7
	Married		8	61.5
	Partnered (not married)		1	7.7
	Single / separated / divorced		1	7.7
	Widowed		2	15.4
Living arrangements	Alone		4	30.8
	With partner / spouse / family		9	69.2
Location of residence	Suburbs		5	38.5
	Countryside		8	61.5
Employment status	Employed full time		1	7.7
	Employed part-time		1	7.7
	Self-employed		2	15.4
	Unemployed, looking for work		1	7.7
	Retired		6	37.5
	Household duties, carer, voluntary work		2	15.4
Current or prior occupation	Professional / higher admin.		5	38.5
	Skilled & clerical		4	30.8
	Semi or unskilled		1	7.7
	Farming		1	7.7
	Military		2	15.4
Finances	Well above average		1	7.7
	Slightly above average		5	38.5
	Average		7	53.8

7.3.1 Reflections on individualised quality of life feedback & the use of graphical summary profiles

A summary of responses from study participants is given in Figure 7.1 which shows the patterns of responses across participants. The thematic analysis coding framework from NVivo with a summary of response frequencies is given in Figure 7.2.

7.3.1.1 Time spent thinking about the quality of life feedback

Nine of the 13 participants (69%) reported that they had spent more than ten minutes independently looking at their graphical summary profile during the study (i.e., in addition to during any verbal guidance they might have received). Six of the thirteen also reported that they had thought about the graphical information after they had completed the study. The length of time these participants had spent thinking had varied however, from two who stated that they had thought about it “*a little bit*”, to two others who reported that they had spent substantial periods doing so – one for over an hour, another who reported she was still continuing to think back to the feedback.

7.3.1.2 Post study review of the graphical summary profile

Participants were asked if they had looked at the graphical profile again after they had finished taking part in the study. Four participants (31%) responded yes, each giving one of the following reasons: to focus on a specific area; to focus on how QoL had changed since participating; to clarify thoughts; and to check answers.

7.3.1.3 Sharing of graphical summary profile with others

Two participants (15%) reported that they had shown the graphical summary profile to someone else, although only one had discussed the profile in detail, with a friend. The other participant had shared the profile with a family member but reported that they had only done so to inform them what they had done in the study. Eleven (85%) of the 13 participants had not shown the graphical profile to anyone else. Reasons given were: it had not occurred to them; they did not believe anyone else would be interested; they felt no need to do so; or they chose not to share the information with anyone else as they felt it was personal and confidential. Five participants reported that they had discussed the

Figure 7.1 Summary of participants' responses to the semi-structured interview questions

Participant no.	Chronic illness	Study 3 – time spent independently looking at graphs (mins) during the Study 3			Thought about feedback since Study 3	Looked at graphs again after Study 3	Showed graphs to someone else	Discussed the feedback (without showing the graphs)	Would share the feedback with someone else, if could	Took action as a result of the feedback	Identified something else that could have been provided to help better use the information	Considered the feedback useful to share with a HP [‡]	Suggested a way a HP [‡] could use the information	Agreed HP [‡] s should be more aware of QoL
		≤ 5	5-10	>10										
P. 55 (male)	✓			✓					✓		✓	✓	✓	✓
P. 50 (female)				✓			✓		✓		✓	✓		
P. 92 (female)	✓		✓		✓			✓	✓			✓		✓
P. 62 (female)	✓		✓								✓	✓	✓	✓
P. 66 (male)	✓			✓						✓	✓	✓	✓	✓
P. 61 (male)	✓			✓					✓		✓	✓		✓
P. 70 (female)	✓			✓	✓	✓					✓	✓		✓
P. 88 (female)	✓	✓			✓	✓	✓	✓	✓		✓	✓		✓
P. 49 (female)	✓			✓	✓	✓		✓	✓			✓	✓	✓
P. 86 (male)	✓			✓	✓						✓	✓		✓
P. 77 (male)	✓	✓										✓		✓
P. 6088176 (female)	✓			✓				✓						✓
P. 74 (male)				✓	✓	✓		✓	✓		✓	✓	✓	✓

[‡] HP = health professional

Figure 7.2 Qualitative coding summary from NVivo

Study 4 Qualitative Coding Summary				
Coding nodes & sub-nodes	Number of Participants	Number of Coding References	Number of Words Coded	Number of Paragraphs Coded
Node				
Pragmatics total	12	63	2,713	100
Comments on graphs	2	2	62	2
Negative effect of feedback	1	1	52	2
Suggestions	10	26	1,251	41
Value of feedback	11	27	1,086	43
Value of verbal feedback	2	4	104	5
SRT model total	12	83	2,702	121
Input function	11	30	831	39
Goal, standard, reference value	5	10	341	13
Comparator	10	16	492	23
Output function	7	14	538	25
Impact on environment	2	2	64	3
Disturbance	7	9	355	13
WHOQOL model total	12	72	2,624	119
Overall Health	1	1	20	1
Overall QoL	6	12	353	16
Environment total	9	25	1,140	44
Finances	2	4	93	4
Health Care	7	17	928	36
Home Environment	0	0		
Information	0	0		
Physical Environment	2	2	56	2
Recreation	0	0		
Safety	0	0		
Transport	1	1	38	1
Physical Health total	6	14	396	20
Activities	1	1	22	1
Energy	0	0		
Medication	0	0		
Mobility	0	0		
Pain	1	1	12	1
Sleep	0	0		
Work	1	4	96	4
Psychological Health total	7	14	547	28
Body image	0	0		
Cognitions	1	1	23	1
Negative feelings	6	9	418	19
Positive feelings	0	0		
Self-Esteem	1	1	62	4
Spirituality	2	2	18	2
Social Relationships total	3	6	168	10
Sex	0	0		
Social Relationships	3	3	84	5
Support	1	1	38	3

study with someone else, but without actually showing them the graphical profile. Three of these had discussed the information with their spouse, one with a cousin and one with a friend. The participant who had discussed it with her spouse reported that the discussion had covered several topics and stimulated conversation about their plans for the future.

Seven participants (54%) stated that they would want to show the graphical summary profiles to, or to discuss them someone else. Of these, four suggested a family member, one suggested a friend, and two suggested their GP, in the event of them developing a health problem. Six participants (46%) reported that they would not want to share the information with another person.

7.3.1.4 Actions as a consequence of taking part in the feedback study

One participant reported that, as a result of taking part in the study, they had become aware that they needed

“to be a little more positive in my thinking” (P.66, male)

However, the majority of participants (92%, $N=12$) verbally reported that they had taken no specific actions.

Participants were asked if there was anything that could have been provided that might have helped them to better use the information they were given. Two (15%) made the following spontaneous suggestions: a) provide a summary of main directions for future reference, or b) provide clearer instructions for the interpretation of particular items (i.e. those that had been negatively framed in the WHOQOL-BREF). After prompting with examples, a further seven participants selected from options they were given: discussion with a doctor or health professional ($N=4$); define an action plan ($N=2$) and participate in a follow-up phone call ($N=1$). Four (31%) responded that there was nothing that could have been provided that would have helped further.

7.3.1.5 *Sharing quality of life information with a health professional*

Twelve participants (92%) stated their belief that QoL information would be useful to share with a health professional (this figure included one of the healthy participants). Most of these 12 felt that sharing the graphical profile would enhance the health professional's understanding of their QoL, including both physical and mental health. More specifically, one participant suggested that it would assist the health professional to gain an understanding of the patient's general attitude towards illness:

“Well I think it is because I think that is a good indication of how fit you are and your view on how you treat any illnesses. It's your attitude isn't it sometimes towards illness” (P.92, female, age group 65-74)

Two participants reported that it would allow the health professional an insight into their (the patient's) lifestyle.

“[it would help them understand] your lifestyle and, you know, there must be pointers there. I mean, you're professional people and they would pick that up, I'm sure they would.” (P.74, male, age group 65-74)

“Well presumably the health professional... would be able to assess whether I was stressed, over-stressed, or whatever, by the situation I'm in”. (P.70, female, age group 70+)

One participant suggested that understanding their QoL might assist diagnosis of health problems:

“Well, he might be able to read something into, umm, say I went along to see him with a problem, and he had that information there, he might be able to use it, you know, to assist in making the decision on what the problem might be.” (P. 86, male, age group 65-74)

Participants were also asked what they would want a health professional to do with QoL information if it were shared with them, other than to improve their general understanding. Two participants suggested that it could be used to give patients health advice (one of these specifically to prevent future health problems):

“Well probably advise me in preparation for down the line, down the years. They having seen it within other patients would say well your best bet was to plan this way or do this way or this is the sort of food you should be eating or don't do those exercises, these exercise might do damage to you.”

(P.55, male, age group 65-74)

Another stated it could be used to suggest interventions or treatment for psychological matters; and a further participant felt it could be used to re-think the stereotypes that health professionals may hold about their particular patient group:

“Well try and think more... stop thinking of my age group as a set thing that's in the past. I don't go back any farther, music-wise, than Elvis Presley and The Beatles. I don't want to sing Daisy Daisy - I absolutely refuse!”

(P.62, female, age group 75+)

Overall, 12 participants agreed that health professionals should be made more aware of the QoL of their patients.

In summary, this part of the analysis provided insight into the spontaneous actions or thoughts of participants after taking part in Study 3. It was found just fewer than half had thought about the feedback after the study and few had looked at the graphical summary profiles again or shown or discussed them with anyone else. Almost none had taken any specific actions as a result of taking part. However a number of suggestions were elicited for improvements to the feedback process and there was almost unanimous agreement that QoL information would be useful to share with a health professional.

7.3.2 Thematic analysis of interview comments

7.3.2.1 Components of the self-regulation theory feedback loop

A thematic content analysis of the data was used to interpret themes within the framework of the SRT model (Carver & Scheier, 1982, 1998) (see Chapter 2, section 2.3). It was found that a number of participants had made comments that were reflective of specific components of the feedback loop. Illustrative extracts are given below.

Input value

The input value component of SRT represents the perception or sensing of a present condition. In relation to current QoL, self awareness was demonstrated in the comments of the majority of participants. For some this was confirmatory:

“In all of those [domains of QoL] I normally feel pretty good about myself.”
(P.55, male, age group 65-74)

“I think from the point of view of the quality of life I have I’m very fortunate.” (P.70, female, age group 75+)

“At least it made me think and realise I was okay, you know what I mean”
(P.86, male, age group 65-74)

For others, completing the questionnaires and taking part in the feedback process had brought about a new awareness, or sense of identity:

“The feedback helped a little and just filling it in made me realise that perhaps things are a lot better than I really thought.” (P.92, female, age group 65-74)

“I felt at the beginning of the questionnaire and towards the end of the questionnaire and all the questions that were asked I felt that I was getting a picture of who I am, what I am” (P.61, male, age group 75+)

“...when I got those graphs back it made me do a double take of my life and think “gosh, that is actually where you are” (P.88, female, age group 55-64)

Goal, standard or reference value

The goal, standard or reference component of the SRT model provides information about what is desired or intended by the individual. Limited evidence was found of this having arisen from the process of feedback of QoL self-judgements, but those themes that were found reflected a mix of perspectives. For one participant, the reference value represented a clarification of the direction his life was taking:

“I think it’s [about] getting a better view of what I am and where I’m going.” (P.61, male, age group 75)

For another, comments reflected a sense of acceptance and a disinclination to make specific plans or to have concrete goals:

“I think you just get on with your life as it is and you don’t necessarily reflect “oh I could, perhaps I could do this” because you do whatever it is as of the day, or the week, or looking ahead as events occur.” (P.62, female, age group 75+)

There was no evidence of participants having identified particular desired or intended states, although one comment suggested that the feedback process could assist in the identification of intended states:

“I think, even at this stage in my life, it would enrich my thoughts and it would probably give me more indicators of the direction to go.” (P.61, male, age group 75+)

Comments from two other participants suggested the identification of avoidance goals – that of wishing to *evade* a possible future condition or to improve an unsatisfactory current condition:

“But I do see a lot of my friends now; some have passed on; they’re going down with hip problems, knee joints and Alzheimers etc. That’s what worries me more than anything.” (P.55, male, age group 65-74)

“...the thing that was most interesting to me was how it brought it home to me “you really are in a bit of a mess here!” (laughs) This is not where you wanted to be at11 all.” (P.88, female, age group 55-64)

Comparator

In SRT the comparator component is the point of reference whereby the input value and reference value are compared. Evidence was found for the QoL feedback providing a catalyst for this process of realisation:

“I don’t want to get too introspective but it’s quite useful to have a bar graph that you can compare yourself to.” (P.70, female, age group 75+)

“I think that’s the other thing isn’t it, it’s managing expectations...And that’s the other interesting thing with that survey, it’s where you think you should be and where you are.” (P.88, female, age group 55-64)

“...you’re dealing with things, and err, you do just do it almost on a subconscious level, you just automatically sort of do things and act on things, and, you know, think things but you don’t necessarily sit down and think “right, you know, let me think about this, this is fine” and so on. So I think, you know, for that, sort of, it’s a very good tool.” (P.49, female, age group 45-54)

“we’ve a far better quality of life and you realise that when you’re looking at feedback and things. You appreciate what you have.” (P.92, female, age group 65-74)

Output function

The output function component of SRT is any behaviour that is initiated with the goal of reducing any sensed discrepancy between the input and reference values. Some evidence was found of this, with the following comments suggestive of deliberate action arising from the feedback process:

“If I’ve got an issue, I’m very conscious now, if I’ve got something wrong with my body, I go and try and get it sorted out fairly quickly.” (P.62, female, age group 75+)

“...perhaps to be a little more positive in my thinking towards life in general rather than matter of fact.” (P.66, male, age group 55-64)

“Yes, it was, coor, this is where you actually sit, this is what’s happened, something’s got to give here. And I had thought of various avenues, but I thought I really must do something actually now proactive. Whether it’s right or wrong I need to take some action because life is not, you know, I can’t go on like this, because it isn’t a proper life.” (P.88, female, age group 55-64)

However, evidence was also found which implied that some participants felt taking action was inappropriate or would be futile:

“I’m not sure I was prepared to take any actions quite honestly.” (P.66, male, age group 55-64)

“...a lot of the things you can't change.” (P.62, female, age group 75+)

“...a lot of the things I don't think I could do anything about, or I've probably already done them or decided that I cannot do any more about it.”
(P.62, female, age group 75+)

Effect on the environment

The SRT model recognises that individuals can create change in their present condition such that a different input perception results. This was evidenced in the comments of two participants who felt that their attitude towards physical health is inherent in how they perceive their situation:

“It's your attitude isn't it sometimes towards illness. Sometimes, you know, if you sit in a chair and not do anything. Sometimes I ache when I've been out on the golf course but I feel, well at least I've walked the six miles and it's what's keeping me reasonably active.” (P.92, female, age group 65-74)

“One's attitude towards any depletion of one's own health is very important and if you've got a negative attitude towards it, it's probably going to make it worse.” (P.70, female, age group 75+)

Disturbance

A recurring theme indicated that participants recognised the impact on their QoL of external influences which they identified as being beyond their control. In SRT these influences are considered to impinge upon the feedback loop and may either reduce, or enlarge, the sensed discrepancy between current and desired states:

“Life goes on and everything's fine until you get something like illness and we've had two in one year that really throws you doesn't it?” (P.92, female, age group 65-74)

“I think things that make me sad or unhappy are long term and you can't often do anything about them because they're because my husband's died so you get a sort of continual loneliness which is not affected by who else you're with or where you are.” (P.62, female, age group 75+)

“I’m moving into, probably, the role of carer because my husband has been diagnosed [as being] in the early stages of dementia. So from that point of view, life’s uncertain.” (P.70, female, age group 75+)

“Well, um, you know, after having a heart attack, you know, you do reflect on things, you know.” (P.74, male, age group 65-74)

To summarise, evidence was found within the qualitative data relating to each element of the SRT feedback loop. Participants particularly expressed recognition that the feedback intervention had encouraged them to think about their QoL and what this meant for them. Although all stages of the feedback loop were discussed, little evidence was found that suggested changes in actions or behaviours that would indicate achievement of the output component.

7.3.2.2 Pragmatic reflections on the process of quality of life feedback

To inform future applications, the data were further examined for evidence of the value participants placed on the QoL feedback process. Value was identified both in terms of a) the practical process of completing the QoL instruments as well as in terms of b) the subsequent individualised feedback:

Value from completing the QoL instruments

“I felt at the beginning of the questionnaire and towards the end of the questionnaire and all the questions that were asked I felt that I was getting a picture of who I am, what I am, and I could use that for the future.” (P.61, male, age group 75+)

“It gave me a different perspective on things that were happening or have happened, or experiences I’ve had and it just made me think about them a little more sensibly and in a linked fashion.” (P.66, male, age group 55-64)

“I think it can help make a difference because it makes you face it. You don’t sit down normally every day and think about the things that are on

that graph. So maybe it just focuses you.” (P.6088176, female, age group 45-54)

Value of the feedback

The graphical summary profiles were specifically referred to as helpful:

“On a general point of view I think that could help an individual. It would focus their mind on “oh, look what I answered there” and it’s quite a clear way of viewing the gaps.” (P.6088176, female, age group 45-54)

“But what I thought was very good about it all was the fact that it actually broke things into little pieces and that made you actually then to look at all the individual little pieces. You know, it’s what you do every day and what you experience every day but to break it down into those little, sort of, chunks and to be able for you to look at it and to look at the different facets of it, I thought that was very useful”. (P.49, female, age group 45-54)

Evidence was also found of participants having appreciated the verbal guidance in addition to the graphical summary profile:

“I mean, in talking to you, it makes you think a little more deeper. It triggers it off in your mind”. (P.55, male, age group 65-74)

“...suddenly you get this graph, you know, survey to do, and talking personally to you, yes it certainly made it much easier to digest.” (P.74, male, age group 65-74)

Suggestions for applying the feedback

Participants offered a number of suggestions regarding how the feedback process could be applied and how it could be useful to health professionals. A number of comments referred to how the feedback could help health professionals to offer individualised advice:

“[Health professionals could] probably advise me in preparation for down the line, down the years. They having seen it within other patients would say well your best bet was to plan this way or do this way or this is the sort of

food you should be eating or don't do those exercises, these exercise might do damage to you” (P.55, male, age group 65-74)

“Also it’s very difficult to give people advice when they don’t want to hear it. You know, you can’t really. But if you’ve got something in front of you that they have filled in, that says actually this is your life... That’s probably actually, for me, the most important thing, that actually they have filled it in, and that’s where they see it. ... And especially if there were options, you know, sort of “there’s a big gap here” I don’t know “in our experience there are five routes out of this”. (P.88, female, age group 55-64)

The transcripts also indicated that participants felt that sharing the feedback with a health professional would support their understanding and treatment of individual patients:

“I think if they could do it when they joined the surgery or something, I think it would give the doctor a baseline... and then if there is a problem the doctor could maybe almost give them the same thing again and if they can’t articulate it, if they can’t pinpoint what the problem is, it would help to, sort of, narrow down the areas between the two of them.” (P.49, female, age group 45-54)

“I deal with a lot of people at the moment with psychological and mental problems and for somebody like that, that would be a fantastic tool to judge the up and downs and what they’re thinking and where they’re at.” (P.49, female, age group 45-54)

“Obviously if any there’s a diagnosis of anything you had, it would help, because your lifestyle is important. How you live is to your health really. And that’s where I think the doctor would come into that equation.” (P.74, male, age group 65-74)

However, not all comments were uniformly supportive and improvements to the feedback process were also suggested:

“I think it would be useful but I can’t see there ever being enough time for the Health Professional.” (P.6088176, female, age group 45-54)

“A bit more information prior might have made me think a bit more deeper about it.” (P.55, male, age group 65-74)

“Maybe produce a little paper to say “do you think you should be looking at this, do you think you should be thinking about this?””. (P.55, male, age group 65-74)

“...perhaps if there’s something that can be spurted out of a computer, that if it sees a big enough gap, and I know it’s a bit set piece but, you know, you should, not should, consider taking some actions, consider yes those things” (P.88, female, age group 55-64)

“I think if one could have a summary of it, it would help for future reference. Because with the memory and so much happening it’s a good thing just to have a sign pointing in one direction and saying “look hold on a minute, look in that direction”. (P.61, male, age group 75+)

7.3.2.3 *Quality of life themes derived from the WHOQOL model*

The data were also examined for themes relating to the facets of QoL specified in the WHOQOL model. Evidence was found relating to aspects within the **Physical Health** domain:

“But I try and keep myself fit. I try and swim every day. I watch my weight, watch what I eat. I watch what I drink. I try and look after myself but I always have done.” (P.55, male, age group 65-74)

“I get frustrated when I can’t do something that I want to do, because my hands are stiff or something like that.” (P.62, female, age group 75+)

“...life at this age, without work, is for me, not on.” (P.88, female, age group 55-64)

In relation to facets within the **Psychological Health** domain, participants commented on concerns about cognitions and on their positive and negative feelings:

“My only big worry about myself it that as you get older you deteriorate mind-wise - I'm certainly beginning to forget more things.” (P.55, male, age group 65-74)

“Normally I'm not an emotional person...” (P.92, female, age group 65-74)

“When I think about negative feelings I feel that they're very destructive and therefore I feel they're to be avoided.” (P.70, female, age group 75+)

“Well I tend to ponder things quite a lot so I sort of go back and worry at it.” (P.49, female, age group 49-54)

Two participants expressed the importance to them of **spirituality**, as relating to QoL:

“...spirituality, so far as I'm concerned, is very important.” (P.70, female)

“I actually thought about the spiritual side of it” [when reflecting on the QoL feedback] (P.49, female, age group 49-54)

Themes were expressed by some participants relating to the **Social Relationships** domain. For some this related to a sense of distancing from family over the life-course:

“I do have children but they're grown up and doing their own thing. I suppose they don't want to listen to Dad's problems.” (P.55, male, age group 65-74)

However, for others, relationships with family remained important:

“I probably, it sound quite unusual, but I do have, partly because I sort of help him out a bit, quite a close relationship with my father.” (P.88, female, age group 55-64)

Participants also talked of **Environmental** aspects of QoL. Access to health care was one facet in the WHOQOL model that was of apparent concern amongst participants:

“I suppose my future is absolute fear and dread because continually on the news, continually from everywhere is how awful treatment is in hospitals, care homes and even in your own home.” (P.62, female, age group 75+)

Others expressed their concern that GP services were better able to support physical rather than psychological problems:

“I think GPs are (sighs) very good with the body and they’re very good at actually looking at all the signs and pointing you off in the direction, which is their job isn’t it these days? But in my experience, I don’t think they, they haven’t, I don’t know whether they get close to, or, maybe I’ve never been to one with a problem “of the mind!” (P.88, female, age group 55-64)

“I think you go and see your Health Professional and it’s really physical what’s wrong with you today sort of things rather than how you are emotionally.” (P.6088176, female, age group 45-54)

A number of participants expressed their appreciation of their locally provided health services, indicating satisfaction with the care they receive:

“I’m very close to my doctor anyway.” (P.61, male, age group 75+)

“at the moment they [my health practice] are very very good there. I mean I couldn’t fault the service we get there at the moment.” (P.77, male, age group 55-64)

“I have a very good doctor to be honest”. (P.50, female, age group 65-74)

The issue of finances was also a recurrent theme, reflecting another facet within the Environment domain and suggesting that financial considerations were a topical issue in the broader social context at the time of the interviews.

“We’re very fortunate that we’ve got reasonable pensions, both of us, and that we can help our children.” (P.92, female, age group 65-74)

“...for me, it was a life living in a ball of cotton wool without any true direction, and an underlying financial worry that the money’s going to run out.” (P.88, female, age group 55-64)

“I know they’re [the government] saying you can handle your finances to pay for your care if it’s subscribed who you can get it from.” (P.62, female, age group 75+)

Although not every facet of the WHOQOL model was evident within the data, the transcripts nevertheless revealed themes relating to aspects within each of the four WHOQOL-BREF domains. This indicated that the holistic nature of the instrument was consistent with the breadth of conceptualisations of QoL expressed by the study participants.

7.3.3 Comparing outcomes by ratings of the helpfulness of quality of life feedback

As all Study 4 participants had previously suggested their belief that the feedback would be helpful to them it was decided that an supplementary exploratory analysis, comparing their WHOQOL-BREF scores with those of Study 3 participants who had rated QoL feedback as unhelpful ($N = 10$), would identify any differences in QoL between the two groups. As shown in Table 7.2, QoL was good for both groups, with domain scores ranging from 56 to 80. However, MANOVA of T1 results found no significant differences between the groups and univariate results also found no significant differences in the any of the domains.

At T2, MANOVA analysis revealed a significant difference between the groups, which was shown in the univariate analysis to be related to the Psychological Health domain (unhelpful group $M = 55.58$ ($SD = 18.05$), helpful group $M = 70.83$ ($SD = 12.91$), $F(1,21) = 5.66$, $p < .05$, $\eta^2 = .21$). This result indicated that those who had rated the feedback as helpful also had significantly better Psychological QoL after the feedback than those who rated it as unhelpful.

Table 7.2 Results of a) MANOVA analyses of between-subjects effects at T1 and at T2, for WHOQOL-BREF domain scores with helpfulness group as the between-subjects factor, and b) univariate ANOVA results with helpfulness group as between subject factor for each WHOQOL-BREF domain at each time point

		WHOQOL-BREF T1				WHOQOL-BREF T2			
Helpfulness		Physical	Psychological	Social	Environment	Physical	Psychological	Social	Environment
High <i>N</i> = 16	Mean (<i>SD</i>)	71.43 (14.40)	66.67 (13.71)	67.00 (16.53)	77.16 (8.21)	72.02 (14.87)	70.83 (12.73)	66.35 (19.72)	79.81 (12.01)
Low <i>N</i> = 10	Mean (<i>SD</i>)	61.07 (24.37)	57.42 (19.97)	64.17 (20.81)	65.53 (18.63)	61.43 (22.76)	55.58 (18.05)	73.33 (20.71)	67.19 (18.59)
		<i>F</i>	<i>p</i>	η^2		<i>F</i>	<i>p</i>	η^2	
Between groups MANOVA <i>df</i> (4,18)		1.26	.322	.219		3.60	.025*	.444	
		Physical	Psychological	Social	Environment	Physical	Psychological	Social	Environment
Between groups ANOVA <i>df</i> (1,21)	<i>F</i>	1.63	1.74	0.13	4.09	1.82	5.66	0.68	3.21
	<i>p</i>	.216	.202	.720	.056	.192	.027*	.419	.061
	η^2	.072	.076	.006	.163	.080	.212	.031	.157

* Significant at $p < .05$

7.4 Discussion

7.4.1 Findings relating to self-regulation theory

The study data were interpreted within the framework of the SRT feedback loop. In earlier studies in the research programme, it had been hypothesised that the process of QoL feedback would support individuals' understanding of their current situation regarding QoL. The qualitative data suggested that this was true in the present study for some participants. Emerging themes evidenced an increased sense of identity and appreciation of QoL both in terms of spontaneous recognition of current QoL. It was apparent that participants recognised that the QoL feedback had acted as a catalyst for comparing current and ideal states. The feedback had brought a sense of realisation of QoL and the meanings that held for individuals. The data suggested that where QoL feedback was valued in this regard, participants had appreciated that it had led them to reflect on their QoL and to focus on specific aspects that mattered to them. Comments also revealed that participants had recognised a sense of direction or an acceptance of where they felt their QoL would be in the future. It was concluded that evidence was therefore found of the operationalisation of the input value, the identification of the goal, standard or reference value, and the comparator components of SRT.

As discussed in section 7.1, the lack of prior studies regarding the behavioural consequences of a QoL feedback intervention meant no hypothesis had been made about whether participants would take particular actions or change their behaviour as a result of receiving QoL feedback. Although earlier phases of the present research programme had found little evidence of actions immediately subsequent to the feedback intervention, investigation of longer term effects remained exploratory. In the present study limited evidence was found for the identification of specific goals or changes in attitudes. Indeed, for some participants, goals were seen to be irrelevant. Although a minority reported some change in attitude, little evidence was otherwise found of the output function component of the SRT model as instances of specific actions to reduce sensed discrepancies between current and ideal states were not reported by participants. How this issue might be addressed will be discussed in section 7.4.4.2.

Participants in the study provided comments demonstrating the significance of the disturbance component of the SRT model. As discussed in Chapter 2, this is concerned with the effect of external influences on individuals' thoughts and behaviours. The impact of the health of family members or changes in personal circumstances was evident in a number of comments. Similarly it was suggested that the uncertainty of life and not being able to anticipate future events and their impacts was an important influence on QoL.

Overall, the qualitative data were able to be effectively interpreted in relation to the feedback loop of the SRT model, indicating that it was an appropriate explanatory thematic framework for the analysis of the data.

7.4.2 Findings relating to the WHOQOL model

Although evidence was not found for every facet of the WHOQOL model, the analysis nevertheless identified themes for aspects of QoL within each of the WHOQOL-BREF domains. Physical health and psychological health were the most commonly discussed domains, although recognition of the relevance of social relationships and environmental QoL was also evident. These findings therefore reflected the broad ranging conceptualisation QoL of the original WHO (The WHOQOL Group, 1995) definition, supporting its validity in empirical research.

7.4.3 Comparing the scores according to ratings of helpfulness

When the WHOQOL-BREF scores of the sample were compared with those who had found the feedback to be unhelpful in Study 3, those who had rated the feedback as unhelpful had also scored their Psychological Health QoL as significantly lower at T2 than those who had found it helpful. This result suggests caution in terms of identifying those individuals for whom QoL feedback might be appropriate. It may be that individuals with particularly poor psychological QoL should not be given QoL feedback because they gain no value from the process, and indeed perceive it to be unhelpful. Screening for anxiety and depression, before offering feedback, may be useful in this regard. Future research should be undertaken to explicitly consider the effects of anxiety and depression on the receipt of QoL feedback.

7.4.4 Insights to inform the future applications of the quality of life feedback intervention

7.4.4.1 Sharing quality of life information

The study found that QoL based advice from a health professional would be welcomed. Participants felt that their QoL information would help health professionals to treat them with greater understanding and relevance. However, few participants reported sharing their QoL information with friends or family, and none had spontaneously shared the information with their GP or other healthcare staff.

It may be that participants chose not to share with family and friends, but that they might be more likely to do so with their healthcare professional, because of the relationship of confidentiality in healthcare. Perceived trust in advice from a health professional may also be a factor in explaining the view that sharing QoL information with a health professional would be useful. As has previously been found in patient groups, people want to talk about their QoL with clinicians and for them to understand those factors that influence their QoL (Detmar et al., 2000; Detmar et al., 2002; Jacobs et al., 2001). It is also plausible that sharing QoL information in a clinical setting may be encouraged if it is seen as part of the remit of the healthcare worker. In future applications, an explicit instruction to share the information might promote the discussion of QoL feedback information, as this was not something that participants had done spontaneously. It is also plausible that endorsement of the feedback by the participants' GP (e.g. completing and receiving feedback in the surgery itself) would reduce any perceived barriers and encourage the use of QoL information in that setting. These possibilities are only conjecture and further investigation is necessary in order to fully understand the apparent reluctance to share QoL with friends and family, yet an ostensible willingness to do so in a healthcare setting.

7.4.4.2 Wanting direction to capitalise on the feedback intervention

In offering suggestions to improve the feedback, a few participants indicated they would like to have further advice as to what actions to take as well as further clarification regarding to which specific aspects they should focus their attention. This was also evident when participants commented on the potential role of healthcare professionals in

using QoL feedback. It was apparent that participants did not solely want healthcare professionals to have a better understanding of them and their lifestyles. They also expressed a desire for health professionals to use QoL information to give them personalised health promotion advice and to offer tailored support and guidance. This request for guidance may, in part, reflect an underlying predilection to hand responsibility for actions to an external source, or to an uncertainty or lack of knowledge about what actions to take. Both possibilities would be fruitful avenues of further investigation.

It may also have been possible that the holistic feedback provided by the WHOQOL assessments was simply too broad and that a more succinct summary would be helpful. Indeed, appreciation of providing information in “chunks” was mentioned and some participants expressed a preference for concise summarisation of the information provided and greater clarity in terms of “flagging” gaps between QoL and Importance. These considerations will inform further development work on the feedback methodology to enhance the utility of the intervention.

7.4.4.3 Pragmatic findings on the feedback intervention

As discussed above, the study findings suggested that further enhancements to the QoL feedback methods could include providing greater clarity about identifying differences and in summarising the information. It might also be helpful to provide guidance in future applications to suggest that those who found the feedback helpful intervention had spent more than 10 minutes independently reviewing the graphical summary profiles. This would present a benchmark to participants of how long they should look at the graphs if they are to have the best opportunity of understanding and assimilating the information they contain. Whether to add additional instruction to share the information is unclear, as a very substantial minority had initially suggested that they would not want to share it with anyone else. Even if applied in a clinical setting, this would imply that sharing the information should not be made mandatory. It would also be helpful to conduct further research to investigate whether reluctance to share related to the feedback *per se*, or whether individuals are uncomfortable with sharing particular topics within the feedback. For example, modesty and privacy concerns may affect the willingness to share information about very personal topics such as sex life and finances.

If, however, participants were comfortable with sharing information with a health professional, the study findings clearly suggested that they would then want tailored lifestyle advice. In order to provide this, healthcare professionals would need to receive appropriate training in the intervention: application of the instruments, interpretation of results, provision of feedback, and provision of any instruction or guidance. Whilst this may be beneficial, it also would change the intervention to one which is seen to be a “provided”, rather than a “self-management tool”. Further efforts to facilitate the use of the feedback by the individuals to whom it applies may thus have greater value in the long term. For example, as a self-management intervention, this approach has the potential to support individuals whose health is not an issue but who could benefit greatly in terms of other aspects of the QoL. This would not exclude the application of QoL feedback within healthcare, but focusing on self-management would have the economic benefits of reducing the financial and time costs associated with administration by healthcare staff.

7.4.5 *Study limitations*

As a relatively small, primarily qualitative study, the findings here gave valuable insight into the reflections and spontaneous actions of participants in Study 3 after receiving QoL feedback. The semi-structured interviews also elicited participants’ views on potential applications in healthcare. However, it is plausible that, had participants not been specifically asked about applications in healthcare, they may not have spontaneously considered this option. Indeed, when asked about whom they would share the information with if they could, only two suggested their doctor, and these comments were caveated with “*if I had a problem*”. It seems likely that without including a question about whether QoL information would be useful to share with a healthcare professional, this link would not have been made.

Similarly, when asked what could have been provided to help participants better use the information they were given, seven of those who responded required prompting with examples before they gave a response. Although this may have allowed them to access suggestions they may have spontaneously reached themselves in time, it is also plausible that these examples led respondents to agree with options they may not have otherwise considered and the evidence is therefore unreliable in this regard.

7.4.6 *Conclusion*

The findings of this study were consistent with those of earlier studies in the thesis. It was clear that people are interested in their own QoL and some value feedback on their self-judgements. QoL information was considered potential helpful to healthcare professionals whose individualised guidance and advice would be welcomed by some participants. Despite this, not all participants would want to share their QoL feedback with health professionals. As in earlier studies, participants did not report taking specific actions as a result of QoL feedback. The conclusion is that, even if QoL feedback is perceived as helpful for the individual, further active intervention ingredients, possibly drawn from other theoretical models, will be necessary if tangible actions are to be subsequently initiated.

CHAPTER 8. DISCUSSION

8.1 Introduction

Since the mid 1990's the collection of data from patients on the outcomes and processes of care has been advocated (Black, Browne, & Cairns, 2006) and considerable effort has also been recently made to improve care quality and efficiency in health care systems. As discussed in Chapter 1, a range of patient reported outcome measures (PROMs) has been developed in order to improve patient involvement and to enhance healthcare managers' appreciation of patient views, by capturing patient perspectives on illness, health and intervention effects. These measures include QoL as well as more traditional functional assessments of health status and disability (Bowling, 1995a). In a review of the effectiveness of PROMs in clinical practice, Fayers (2008) conceded that the measurable benefits of using PROMs in patient management may be modest. He suggested that this might be because good clinicians already collect and discuss PROM data without using prescribed questionnaires or because patients already have an expectation that their opinions will be sought and considered. He nevertheless asserted that PROMs remain important and can be useful in bringing about positive effects on clinical outcomes. More specifically in the context of chronic illness, PROMs have been asserted to have particular value in enabling patients and health professionals to jointly identify goals and priorities for the future (Marshall et al., 2006).

In line with these policy developments in healthcare, the recent focus of QoL research has also been to move towards person-centred studies (Hahn, 2012; Iris, Debacker, Benner, Hammerman, & Ridings, 2012; Skevington & McCrate, 2012). In a recent 2012 members' newsletter, the International Society for Quality of Life Research (ISOQOL) announced its next conference theme as "*The Journey of Quality of Life Research: A Path Towards Personalized Medicine*" (2012a). This underlines the current movement towards targeted treatments in healthcare and to investigating QoL at the level of individuals, in addition to a traditional concern with the QoL of populations and particular groups.

Individualised assessment requires measures that have precision and which have been developed with user involvement, not just by experts or academics (Skevington & McCrate, 2012). The WHOQOL instruments were developed in collaboration with users to reflect the language and concepts that they understood and they also have the good psychometric properties that are needed for use with individuals (Skevington, Sartorius, et al., 2004). As discussed in earlier chapters, recent research using WHOQOL measures has also begun to investigate the importance attributed to aspects of QoL, as well as the core constructs of self-reported QoL. This seems to be an emerging new area of investigation and demonstrates an acknowledgement that understanding the perceived importance of dimensions of QoL provides an important heuristic for those who deliver health and social care services.

8.1.1 Aims of the thesis

In Chapter 2 of this thesis, the concept of self-regulation theory (SRT) was introduced as a homeostatic construct by which human behaviour is presented as an attempt to reduce sensed discrepancies between an individual's judgement of their actual and desired states. Subsequent chapters sought to investigate the mechanisms for, and effects of, facilitating individuals to identify these differences in relation to their own QoL. The underlying premise of the programme of research was that subjective ratings of QoL could be applied to facilitate the identification of these differences. It was hypothesised that this, in turn, would bring about a positive effect on individuals' wellbeing.

The work in this thesis thus aimed to develop the basis of a self-management tool, using QoL information at a person-centred level. Its specific purpose was to design an effective and acceptable protocol for giving individualised feedback on self-ratings of QoL.

The primary research questions, as stated in Chapter 2, were:

1. What effect does thinking about one's own QoL have on an individual's later assessments of his/her wellbeing?
2. Does receiving individualised feedback on QoL judgements and the importance of QoL have a positive impact on later consideration of core QoL and the importance of its various aspects, mood and QoL-related goal orientation?

3. What reflections do individuals have in relation to thinking about their QoL and the process of individualised QoL feedback?

Chapters 1 and 2 introduced the context to the thesis, outlining the rationale, theory, and research questions. Chapter 3 described how the methodology was developed for subsequent application to answer the overall research questions of the programme of research. Chapter 4 provided an account of a pilot study to investigate the effect of the act of thinking about QoL on subsequent wellbeing. Chapter 5 examined the effect on QoL of providing structured QoL feedback in terms of WHOQOL-BREF and WHOQOL Importance scores. Chapter 6 detailed a psychometric investigation of the QoL measures employed in the thesis and Chapter 7 returned to the question of individuals' usage of QoL information after receiving individualised feedback and of their reflections on the feedback intervention. The current chapter provides a summary and critique of the thesis including findings, conclusions, contributions and a consideration of future avenues of research.

8.2 Summary of Main Findings

8.2.1 Just thinking about one's quality of life alone had no subsequent effect on wellbeing

Although designed as a methodological development study, the findings of Study 1 suggested that participants were interested in understanding more about their QoL, and that reviewing their self-ratings could provide an opportunity for reflection. Building on this positive endorsement, Study 2 was a "proof of principle" pilot study to investigate whether the cognitive process of thinking about QoL could bring about a change in terms of self-judgements of wellbeing, as measured in terms of QoL, mood and QoL-related goal orientation. The results of the statistical analysis of study data, however, found no such measurement effect, and established that this was also true regardless of the type of method applied to facilitate the consideration process. This was consistent with earlier studies which found no effects from QoL instrument completion on emotional, social or family wellbeing in cancer patients (Velikova et al., 2004) or self-reported QoL for lung transplant patients (Santana et al., 2010). Although participants' post-study reflections suggested they perceived some limited effects in terms of the way

they thought about their QoL, in the absence of effects in terms of the quantitative outcomes, it was concluded that simply thinking about one's QoL, was not sufficient to bring about measurable changes in subsequent wellbeing.

8.2.2 Receiving individualised feedback on quality of life was associated with a positive effect on wellbeing

The findings of Study 3 demonstrated that the additional mechanism of receiving individualised feedback on subjective judgements of was associated with increased scores of psychological health, as measured by the WHOQOL-BREF. This finding concurs with previous studies where QoL feedback has been associated with improved psychological QoL (De Wit et al., 2008; Velikova et al., 2004). Within the Study 3 data, results demonstrated no superior effect for either mode of reviewing feedback, (i.e. providing verbal guidance to review the feedback of graphical summary profiles in a one-to-one interaction, as opposed to participants reviewing feedback profiles by following a set of written instructions). Prior evidence suggested that patients want to discuss their QoL (Detmar et al., 2000) but differences between the effects of verbal guidance and written instructions for reviewing feedback had not previously been tested.

8.2.3 Receiving individualised feedback was an acceptable and appreciated method of facilitating improved understanding of quality of life

Qualitative data were gathered from all four studies that gave valuable insight into participants' reflections on QoL and the methodologies applied to facilitate this consideration. Results indicated that participants found taking part in the research to have been valuable in supporting their understanding of their own self-judgements of QoL. A brief summary of the specific findings from these evaluations are given below:

8.2.3.1 People were interested in their quality of life

Across the programme of research, results suggested that many participants were interested in QoL and that being involved in the research had helped them to appreciate their own situation. Some reported this to be self-affirming and felt it had reminded them of the positive aspects of their lives. The qualitative data also indicated, as a recurring theme throughout the research, that thinking about QoL was often a novel experience. A

number of participants reported a prior lack of consideration of the topic, but also described how taking part had proved to be a catalyst for reflection or had prompted them to attend to aspects of their QoL that they had previously not contemplated.

8.2.3.2 *Receiving individualised quality of life feedback affected thinking about quality of life*

Participants in both Studies 2 and 3 expressed their belief that taking part in the research had changed the way they thought about their QoL. However, this view was more evident amongst Study 3 participants, that is, those who had received guided individualised feedback on their QoL. A large minority of participants in both these studies also reported perceived changes to their mental health, although the direction of effect was not elucidated. Throughout the studies few participants reported more concrete changes, i.e. changes to their plans and expectations, physical health *per se*, environment or social relationships.

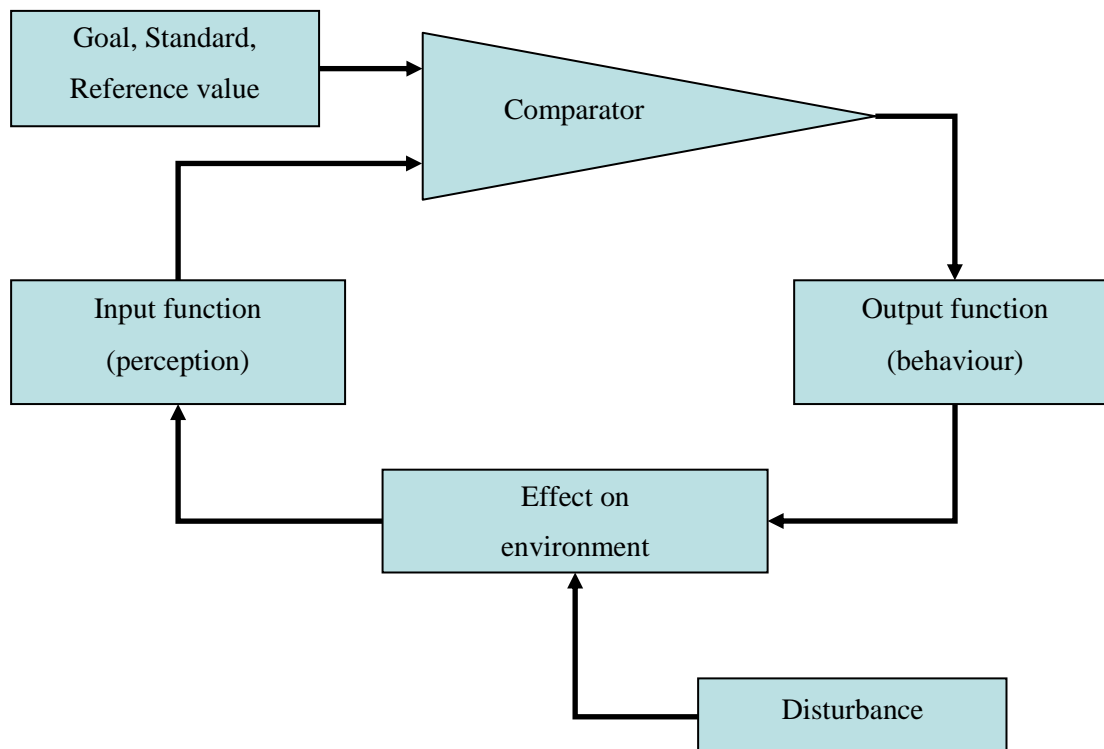
8.2.4 *Behavioural change was not a spontaneous outcome of the individualised feedback intervention*

The results of Study 1 suggested that older adults employ short-term adaptive strategies for living rather than identifying and pursuing longer term goals. Indeed, the results indicated that older adults often felt the concept of goals to be irrelevant at their stage in life. However, neither did the results from the wider samples in later studies, indicate the generation of goals or plans as a consequence of taking part in the research. Nevertheless, qualitative data did provide some evidence that understanding one's QoL better, and receipt of feedback, could elicit a state of behavioural preparedness. Here participants articulated their intentions to make more concrete changes, whether these were attitudinal (e.g. trying to think more positively), or behavioural (e.g. taking more exercise). However, no tangible behaviour change was reported.

8.3 Relating the Findings to Self-Regulation Theory

The research in this thesis was grounded in Self-Regulatory Theory (Carver & Scheier, 1982, 1998), the basic unit of which – the negative feedback loop – is given in Figure 8.1. (See also Chapter 2.)

Figure 8.1 The feedback loop (Carver and Scheier, 1982, 1999)



The results of Study 2 suggested that thinking about QoL could bring about a better understanding for participants of their current QoL, or the input value in SRT. In Study 3 it was demonstrated that adding the feedback mechanisms also facilitated the identification of reference values – a perception of desired QoL and acted as a catalyst for the comparator stage of the SRT feedback loop. The qualitative findings of Study 4 supported these assertions with participants reporting that the feedback had brought about greater comprehension of current QoL and a realisation of where that differed from desired QoL. Few participants in any of the studies reported the spontaneous development of concrete plans for further action. As such, it could be concluded that

attainment of the output function was not fully evidenced. However, as mentioned above, indications of behavioural preparedness were identified, as some participants had clearly begun to consider what changes they could make, particularly in terms of ways to reduce negative feelings or to promote positive thinking. In developing SRT, Carver and Scheier (1998) specified that the purpose of the feedback system is not to *cause* behaviour *per se*, but to bring about changes to diminish the perceived gap between present status and goals, which may, or may not, be related to concrete behaviours. In this context the evidence of behavioural preparedness; intention to reduce negative feelings; and acknowledged changes in thinking about QoL that was found, could be argued to represent some degree of achievement of the output function.

Without a theoretical framework, this thesis would have identified the effects of QoL feedback, but an explanation of the processes by which these effects were achieved would have been missing. SRT was demonstrated to be an appropriate model through which the mechanisms supporting the feedback outcomes could be considered and explanations postulated for the results that were found.

8.4 Methodological Developments

Study 1 had sought to develop the initial methodological aspects of the proposed intervention by evaluating any novel components to determine their feasibility, face validity and acceptability to participants. Results identified those refinements to the original feedback methodologies that were needed, both in terms of verbal guidance and written instructions for reviewing the graphs. Enhancements to prose-based formats for thinking about QoL were also established and integrated in later studies. Further details of specific enhancements were given in Chapter 3.

Study 1 had also found that it was necessary to flag up where the differences lay between a participant's QoL and the importance of these aspects, as this was not something to which they spontaneously attended. Although amendments to the protocol were made to this effect, the findings of Study 3 similarly reinforced the importance of this essential element of the feedback. Study 3 results also revealed a further need to indicate the ways in which participants could seek to reduce discrepancies, if they chose

to do so. It was deemed necessary to point out that they could either a) take actions to improve their QoL for that facet OR b) reconceptualise the importance they attach to that facet.

Other methodological enhancements to improve the interpretability of the WHOQOL graphical summary profiles were identified throughout the course of the research but have yet to be explored empirically, e.g. re-labelling facets, as presented in the profiles to minimise confusion; providing facet definitions to assist understanding; and ensuring consistent language is used for both WHOQOL-BREF and corresponding WHOQOL Importance items. These considerations were discussed in more detail in Chapter 5. Future studies will need to test any subsequent amendments, both in terms of the feasibility and acceptability of administration, but also to establish whether these improvements extend or strengthen the efficacy of the feedback intervention.

Study 4 revealed potential enhancements to any guidance given to individuals for additional review of their QoL following feedback. For example, it may be helpful to suggest that participants attend to the graphical summary profiles for minimum of an additional 10 minutes in order that they have the time to focus on individual aspects, as was reported to be helpful by some participants. Suggesting that participants share the graphical summary profiles with a health professional may also enhance the feedback as most participants reported that this would be useful. Such instructions would benefit from further research but could be helpful in enhancing the effects of the feedback intervention.

8.5 Research Strengths and Contributions

8.5.1 Combining quality of life and importance

As was pointed out in Chapter 5, several studies have investigated the effects of feeding back information on QoL (De Wit et al., 2008; De Wit et al., 2010; Gutteling et al., 2008; Hilarius et al., 2008; Rosenbloom et al., 2007; Santana et al., 2010; Velikova et al., 2004). Others have investigated the importance of QoL (Baile et al., 2011; da Rocha, 2011; Lidstone et al., 2003; Molzahn et al., 2011; Molzahn et al., 2010; Skevington &

O'Connell, 2004; Snyder et al., 2011; C. Wu, 2009). However, no studies were found where the effects of feedback of *both* QoL, *and* the importance individuals attach to its aspects, have been investigated. Including both constructs allows individuals to better understand and appreciate their current state and to recognise those aspects of QoL that might be a priority for action i.e. those aspects they consider to be highly important but where QoL is less good. The present programme of research developed an original methodological approach, facilitating individual participants in reflecting on their QoL and importance scores *in combination*.

8.5.2 *Developing a unique protocol for individualised quality of life feedback*

By developing a unique protocol for feeding back QoL information, a new tool has begun to be developed which combines QoL and Importance information in a systematic and individualised way. In previous studies QoL information has mostly been fed back to health professionals (Gutteling et al., 2008; Rosenbloom et al., 2007; Velikova et al., 2004) and while guidelines for interpreting the information were provided in one study (Santana et al., 2010), this has not always been so (Hilarius et al., 2008). The present programme of research investigated a protocol for providing feedback to individuals in a way which was designed to deliberately focus attention on gaps between core QoL and Importance. Whilst further work is required to establish the efficacy of this approach, the basis for a psychological intervention has nevertheless been proposed.

8.5.3 *Technical innovations*

In order to provide the combined graphical summary profile, a new presentation format was designed, based on prior work at the University of Bath (Skevington & Day, unpublished). Novel algorithms were developed in Microsoft Excel to enable generation of the extended graphical summary profiles using raw scores from both WHOQOL-BREF QoL and WHOQOL Importance questionnaires. A new SPSS syntax was also written in order to transform raw WHOQOL Importance scores to a format comparable with the domains of the WHOQOL-BREF for the purposes of statistical analysis. These new and original approaches were applied in the programme of research, extending the capability of the presentation of WHOQOL data such that it is able to be feasibly and effectively used in providing individualised QoL feedback.

8.5.4 *Extending quality of life research*

As was also reported in Chapter 5, prior studies have primarily sought to understand the impact of QoL feedback on processes within healthcare systems, such as patient-physician communication (Hilarius et al., 2008; Santana et al., 2010; Takeuchi et al., 2011; Velikova et al., 2004; Velikova et al., 2010). However, where studies have investigated the QoL of participants themselves as an outcome, this has tended to be a secondary focus. The studies described in this research took a fundamentally person-centred focus that was outside the healthcare system, concentrating on the utility of QoL information in terms of improvements in the wellbeing of individuals in the community. Unlike prior QoL feedback studies, the effects described in the present research were not mediated either by medical consultation processes or by healthcare professionals. Indeed it has been asserted that these types of effect may be obscured in conventional patient trials by physician effects (Fayers, 2008). As such, conducting research outside of clinic or healthcare environments diminished the possibility of clinician contamination.

Those previous studies that have investigated feedback of QoL to patients have also mainly focused on people living with various cancers (Hilarius et al., 2008; Rosenbloom et al., 2007; Velikova et al., 2004). In the present research both healthy and chronically ill samples were used. The QoL and challenges faced by these groups are undoubtedly very different from those faced by people with acute or immediately life-threatening illnesses. By extending the research base with these groups, a feedback protocol was developed that may be more widely applicable in supporting psychological wellbeing. The results of this research are also intended to contribute to, and extend the existing body of literature on the potential application of QoL information with patients and healthy adults.

Finally, no previous research has been conducted that has investigated the effects of QoL feedback on QoL-related goal orientation or the importance individuals attribute to aspects of QoL. These issues could both be considered elemental stages in SRT, in terms of providing the reference value against which people compare their current state. Including these analyses in the research therefore added valuable insight into the practical effects on these constructs of receiving individualised QoL feedback.

8.5.5 Psychometric analyses

In Chapters 1 and 6 it was asserted that applying QoL outcome measures with individuals requires the use of high calibre precision instruments (Skevington & McCrate, 2012). Analysing the psychometric properties of the QoL measures used was not part of the programme's research questions, nevertheless these analyses contribute to the existing literature regarding the reliability and validity of the measures employed.

As a measure of reliability, the internal consistency of the WHOQOL-BREF was found to be good, in line with previous research (Kalfoss et al., 2008; Skevington, Lotfy, et al., 2004; W. Taylor et al., 2004; The WHOQOL Group, 1998a; Van Esch et al., 2011). Factor analysis also supported the construct validity of the WHOQOL-BREF measure. Testing the validity of the WHOQOL-BREF further, good discriminative validity was established for all domains of the measure in relation to health status groups identified from health scores from within the measure and moreover also from health scores from an independent measure - the EQ-5D VAS. As expected, correlations between the domains of the WHOQOL-BREF showed significant associations of moderate size. These results indicated again the strong psychometric properties of the WHOQOL-BREF thereby indicating that it is a useful PROM and one which can be reliably used with individuals.

As has been previously found, the internal consistency of the WHOQOL Importance measure was also confirmed (Molzahn et al., 2011; Molzahn et al., 2010). However, the construct validity of the WHOQOL Importance in relation to the WHOQOL-BREF domain structure had not previously been tested prior to the present study. Results were mixed, indicating some lack of fit. Further research will be valuable in future in establishing the underlying structure of the WHOQOL Importance and investigating whether it is indeed different from that of the WHOQOL-BREF. Unlike the WHOQOL-BREF, the WHOQOL Importance was found not to discriminate between health status groups. This did not imply it lacks discriminative validity *per se*. Rather it was concluded the importance of QoL may be a separate construct independent of actual QoL. As few studies have investigated the WHOQOL Importance to date, valuable opportunity exists to test this measure further in the future.

Interestingly, convergent validity analyses found no association between the WHOQOL-BREF and WHOQOL Importance domains. This had not been previously tested but it was concluded that findings suggested the two measures are independent and that the information they provide is dissimilar. This again does not imply lack of value, but simply that each instrument may measure a different QoL construct. It has been postulated that the items in the WHOQOL-BREF and the WHOQOL Importance assess different perspectives on QoL in spite of their shared conceptual origins (Skevington & O'Connell, 2004). It seems plausible therefore that individuals' self-ratings of QoL are idiosyncratic and independent their assessments of their core QoL. For example, while one person with poor health may resent their dependence on medication, another may be accepting of the same treatments. While both may rate their physical QoL as poor, their assessments of the importance of "being free from dependence on medication" (one of the WHOQOL Importance items) would be very different. Given the paucity of investigation into association between ratings of core QoL and the importance of QoL, further research would be of much value in this area. There may be a number of potential explanations to support the assertion that core QoL and the importance an individual attaches to its aspects are different constructs. Perhaps the process of response shift (introduced in Chapter 2), which has provided an explanation for shifting reference values in assessments of QoL, operates differently in relation to changing conceptualisations of importance. It is also possible that cohort effects lead to differences in importance for groups of people with seemingly similar QoL. For example, Blanchflower and Oswald (2004) postulated that older adults relinquish their aspirations later in life. This type of change would mean some QoL aspects may become less important, even if core QoL remains unaltered. Similarly it is also plausible that the active pursuit of specific goals may inflate individual's assessments of the importance of those aspects, again independently from their self-judgements of core QoL.

As expected correlations were found between the WHOQOL-BREF and the GOSS-Q, between the WHOQOL-BREF and the EQ-5D, and between the GOSS-Q and the EQ-5D, confirming the convergent validity of these measures.

8.5.6 *Mixed methods*

One of the strengths of this research was its use of mixed methodologies. As was seen in the results of each empirical study, this added value in three ways 1) eliciting qualitative data to substantiate quantitative findings; 2) providing insights into the acceptability and feasibility of study processes, and 3) highlighting perceived effects that were otherwise masked in statistical analyses. It has been argued that mixed methods are founded in pragmatism and that quantitative research alone, whilst being rigorous and replicable in clinical studies, may lose the subtlety and distinctions of participants' experiences (Ring et al., 2010). By employing complimentary approaches a richness of insight was achieved which in turn allowed a holistic investigation of participants' self-judgements of QoL.

8.6 **Research Limitations**

Throughout the chapters, the limitations of the individual studies were acknowledged and discussed. Those that apply across the present research more generally are outlined here.

8.6.1 *Confounding variables*

It is entirely plausible that the pre-post test study designs employed in this research allowed for confounding variables to influence the outcomes measured. This opportunity for bias was exacerbated by the nature of the research in that it was not laboratory based, but rather administered by post, online, or in community health settings. As such, control over potential external influences was limited. In Studies 2 and 3, for example, participants were asked to complete T2 measures immediately after reviewing their graphical summary profiles. However it was not possible to control the extent to which they followed this instruction. Furthermore, within the studies, the gap between the collection of T1 and T2 data could conceivably have allowed other events in participants' lives to affect their self-judgements of QoL at post-test. This potential for bias was particularly obvious when measures were administered by post, as an inevitable delay occurred whilst graphical summary profiles were generated and returned to participants. Moreover, participants in Study 3 who received verbal guidance were not

always immediately available and appointments for their feedback discussions had to be made at a time convenient to them, allowing the possibility of delay. Replicating the studies in a more controlled setting, perhaps at clinic visits, would help in reducing extraneous influences and methodological biases in future research.

8.6.2 Experimenter effects

Another limitation within the programme of research is that it was designed and administered by a single researcher. In such cases there is a risk of ascertainment bias. Conducting research within a multidisciplinary team and with a number of different administrators would reduce bias and potential experimenter effects. Sampling across multiple centres would further enhance the findings. Nevertheless, the regular and rigorous supervision of the methodologies and analyses throughout the research programme was determined to be the most pragmatic method of reducing bias in the present research.

8.6.3 Direction of self-perceived change

A general limitation across three of the studies in the research relates to the design of the post-study evaluation of change questionnaires. Participants were routinely asked whether their QoL or their ways of thinking had changed, and by how much. However, they were not asked in which direction any changes had occurred. Investigating whether changes had been positive or negative would have given greater insight into the self-perceived effects of QoL information and including this question in future evaluative studies will add to the richness of the data.

8.6.4 Sample limitations

Convenience, purposive and quota sampling strategies were used in the research and all involved community samples. Employing different strategies was deliberate in order to meet the specific aims of each study, however, it resulted in an inconsistency of approach across the research as a whole. For example, the Study 1 sample comprised older adults but in Study 2 the sample was broadened to all adults. Study 3 introduced a quota sampling strategy to achieve a main sample of people with chronic illnesses and a healthy control group. This study also only used data from those participants who had

completed both pre- and post-test measures although the psychometric study in chapter 6 used baseline data from all prior participants. Study 4 participants were a sub-group of Study 3 participants purposively drawn from those who had found the feedback intervention to be helpful.

In Studies 1 and 2, sample sizes were very small and results must consequently be viewed with a degree of caution. However, the larger sample in Study 3, and combining of the data from earlier studies for the psychometrics analysis, resulted in sample sizes that were more adequate for the analyses conducted. Access to larger patient groups or established health clinics, plus additional research resources would have been beneficial in terms of sample sizes. Future research would benefit from extension to wider populations and larger samples would enable consideration of effects at the levels of sub-groups within the overall data.

8.7 Next Steps

Having established that QoL feedback was associated with people's perception of wellbeing in terms of increased scores of psychological health, the logical next question is how to extend this in such a way as to promote prioritisation of subsequent self-regulatory efforts to bring about active behavioural change and support sustained psychological wellbeing. Further work that might be useful in this regard is explored below. As was pointed out in the methodological limitations noted in Chapter 5, this future work should use a more stringent study design than was practicable in the current research by employing control conditions against which to measure intervention effects.

8.7.1 Intervention design

As discussed earlier, further refinements to the feedback tool have been identified and can be applied in future revisions. Testing with larger and more diverse populations would also be worthwhile. Furthermore, if the verbal guidance approach is to be used in healthcare or community settings, those involved in giving that guidance will need training, and ongoing support will need to be designed and implemented to ensure consistency and quality in its delivery.

In future applications it will also be necessary to give due consideration to the mechanisms of administration of the tool. The systems and computer applications used in the research were appropriate to achieving the research aims, but need further development if they are to be administered in a healthcare setting. Automating the graphical summary profile offers a number of challenges. Although a website application currently exists where individuals can complete the WHOQOL-BREF and print output graphs online, this will require re-programming to include the WHOQOL Importance questions, graphical summary profiles and accompanying feedback guidance. Alternatively delivery via CD-ROM technology or mobile phone type “Apps” might be preferable. Clearly, the effective application of this tool in wider settings will necessarily require further investigation into the best, and most appropriate, delivery mechanisms.

8.7.2 Feedback application

It was mentioned in Study 3 that an alternative feedback strategy had to be used for two participants who saw their QoL as particularly poor. It therefore seems appropriate to note the general feedback protocol developed in this research may not have universal applicability nor should it be assumed to work for everyone. Prior to instigating a general application, it is recommended that consideration is given to whether screening for anxiety and depression may be helpful in determining its suitability. However specific efforts into the development of an alternative tool are likely to be necessary if this approach is to be applied to positive effect for people with anything other than good mental health or with particularly poor QoL, such as in cases of significant illness or financial poverty.

It would also be of value to consider whether the feedback has greatest efficacy with people who are already in a state of behavioural preparedness to make changes in their lifestyle or cognitions. While the results from this research demonstrated a positive psychological effect from receiving feedback, this did not translate into measureable behaviour change. Consideration of any contextual cues that might lead to individuals being more likely to embrace QoL feedback and to act on the information was outside this work. It is plausible that, for example, health threats, diagnosis of a chronic illness or specific and important life events may provide a window of psychological

opportunity in which QoL feedback can be applied to best effect. For example, facing health threats has been found to act as a catalyst for re-evaluating goals and priorities, for re-establishing a sense of self and creating a sense of resilience (S. E. Taylor, Kemeny, Reed, Bower, & Gruenewald, 2000; S. E. Taylor et al., 1984). Indeed it has been suggested that a number of positive outcomes may result from stressful events including the enhancement of coping skills (Shifren, 1996; S. E. Taylor et al., 2000). Such findings suggest that QoL feedback might be appropriate in such circumstances.

8.7.3 Combining feedback with other approaches

Rather than waiting to apply QoL feedback at a time of externally induced opportunity, it may also be possible to bring about a readiness to change by combining individualised feedback with other psychological interventions. These possibilities require further investigation but it seems likely that secondary components relating to behavioural change could be developed and applied alongside QoL feedback to promote and enhance its effects. Approaches that might constitute these additional components are discussed below.

8.7.3.1 Mood and social comparisons

Given the acknowledgement of emotional experience as a consequence of the feedback loop in SRT, it is reasonable to conclude that affect too, may influence the formation of health beliefs and behaviours. Negative mood has been found to be associated with higher levels of reporting aches and pains and lower confidence to carry out illness-alleviating behaviours (Salovey & Birnbaum, 1989) and to have a deleterious influence QoL in chronic illness (Ekici et al., 2006; Friedman et al., 2005). Conversely, seeing oneself as invulnerable to future negative events has been found to be accentuated among happy individuals (Salovey & Birnbaum, 1989). Although the tendency to experience positive emotions might be considered dispositional, it can be influenced by interventions or activities that elicit more positive feelings (Salovey, Rothman, Detweiler, & Steward, 2000). As discussed in Chapter 2 for example, social comparison theory proposes that individuals make sense of their world by comparing themselves with others (S. E. Taylor et al., 1984). Downward social comparisons (i.e. with individuals considered to be worse off), have been suggested to represent an effort to

regulate emotions by making the individual feel better regarding their own circumstances. Similarly upward comparisons (i.e. with those considered better off) can be used in problem-solving efforts and as a means of meeting emotional needs by providing motivation, hope and inspiration (S. E. Taylor & Lobel, 1989). Positive comparisons have also been found to result in beneficial self-evaluations (Rogers, Gately, Kennedy, & Sanders, 2009). The current research found positive effect of QoL feedback on psychological QoL but little effect specifically relating to mood as measured by the PANAS. Adding mood enhancing components such as a guided generation of social comparisons may be fruitful in bringing about improvement in mood and thus supporting subsequent behaviour or attitudinal change.

8.7.3.2 Implementation intentions & self efficacy

As mentioned earlier in this chapter (section 8.2.4) the present research found evidence of behavioural preparedness or intention to change, even if actions had not been taken. As discussed in Chapter 2, theories of intentional behaviour change, such as the Theory of Reasoned Action (Fishbein & Ajzen, 1975) and the Theory of Planned Behaviour (Ajzen, 1985) are based on the premise that intentions or goals are predictors of behaviour. Also mentioned was the Health Action Process Approach (HAPA) (Schwarzer, 1992, 1999; Schwarzer & Fuchs, 1995; Schwarzer & Fuchs, 1996; Schwarzer & Renner, 2000) which also acknowledges the roles of motivation and volition. However, people do not always behave in ways that are consistent with their intentions or motivations. Indeed, in a conceptual and empirical review of research into the intention-behaviour gap, Sheeran (2002) demonstrated that the majority of intentions to adopt new behaviours are not subsequently followed by actual change.

The notion of implementation intentions (Gollwitzer, 1993) was introduced in Chapter 2 as specific if-then plans for actions to achieve particular goals and Study 1 (Chapter 3) tested the feasibility of including implementation intentions in a goal setting component of the feedback intervention. However the task was determined to be inappropriate and unwieldy for the participants in that study. Nevertheless, this does not suggest that it may not be of value in supporting the translation of individualised QoL feedback into achievable behavioural goals in future designs. In the context of SRT, future studies may

benefit from investigating the role of implementation intentions in mediating the relationship between the comparator and output components of the feedback loop.

Allied to implementation intentions, the concept of perceived self-efficacy was also discussed in Chapter 2 and applied in Study 1. It has been asserted that self-efficacy is considered important for action and that people with high self efficacy tend to put considerable effort into goal attainment (Sniehotta et al., 2005). It could be helpful in future studies therefore to understand the relationship between self efficacy and the receipt of QoL feedback by including a measure in future studies. It may be that the effects of receiving feedback are considerably greater in individuals who are self-efficacious. In turn this may indicate that future efforts to encourage self-efficacy, in combination with other strategies for actions, would bring about greater effects from a QoL feedback intervention.

8.7.3.3 Mental contrasting

Another self-regulation strategy mentioned earlier (Chapter 2) that might prove helpful is mental contrasting. As discussed, imagining a desired future and reflecting on a respective negative reality has been proposed to be a means of motivating people to actively self-regulate by translating thoughts about expectations of success and the value of incentives into a goal commitment (Stadler et al., 2010). This approach is similar to the present research and has been demonstrated to facilitate behaviour change in laboratory experiments (Oettingen & Stephens, 2009). Again, future research may benefit from exploring how mental contrasting could contribute to the efficacy of a QoL feedback intervention.

8.7.3.4 Self-judgements of quality of life and the role of response shift

Not only do QoL perceptions vary between individuals, but they also vary within an individual over time (Carr et al., 2001). Periods of adversity, such as ill health, create a threat to the continuation of a person's preferred and desired activities. Yet those faced with such threats often fail to show evidence of the consequent reduction in their QoL (Carver & Scheier, 2000). The concept of response shift (Sprangers & Schwartz, 1999) was elucidated in Chapter 2 and it was pointed out that the recalibration of standards

may be an important mediator of processes of adaptation (Schwartz et al., 2007; Schwartz et al., 2006; Sprangers & Schwartz, 1999).

It was decided that consideration of response shift was outside the remit of the present research as it was not intended to investigate responses to life events or health threats. Nevertheless seeking to identify and measure this process may be pertinent in future studies to try to gain an understanding of the psychological mechanisms at work. Furthermore, integrating the concept of response shift would not conflict with the SRT framework that was found to be valuable in the present research. Indeed, Sprangers and Schwartz (1999) explicitly stated that the response shift model has similarities to SRT and that, rather than replacing such a theory, it can provide additional explanatory power. In the same way, Carver & Scheier (2000) asserted that the resetting of reference values accounts for the same recalibration concept proposed by response shift. Previous research, using cognitive interviewing, has found that response shift can be promoted by individuals' use of reference frames (Robertson et al., 2009). Future studies could use similar techniques to try to uncover how response shift may be influenced by a QoL feedback intervention.

8.7.4 Aims of future applications

Subject to further refinements and testing, the feedback protocol developed in the present research may be applied in a number of settings. Within healthcare, the WHOQOL-BREF and WHOQOL Importance questionnaires could be used to great effect as generic PROMs. This would provide valuable data, not only regarding the functional effects of care processes and medical procedures on QoL, but also would give insight into how these interventions affect individuals' priorities and concerns about their QoL. This in turn might inform individualised and targeted approaches to treatments and care. Evaluating outcomes from this type of QoL PROM in healthcare settings would require consideration of appropriate measures. These might include clinic attendance rates, adherence to medications or more clinical outcomes such as rates of condition-specific complications or maintenance of treatment regimes rather than early escalation of care due to premature health decline.

Furthermore, adding the feedback protocol into existing healthcare practices would allow patients to play a greater part in their care. Understanding QoL and the relative importance of its various aspects would help patients to understand their unique issues and to share in decision making processes. It would also provide a foundation for improved self-management in terms of ongoing health behaviours. Prior research has suggested that self-management interventions can have a positive effect in chronic illnesses and this suggests a potential avenue for the future application of this research (Ditewig et al., 2010; Labrecque et al., 2011).

More generally, the feedback protocol could also be used to support psychological wellbeing outside of traditional healthcare systems. Not necessarily related to physical health, it could be applied to help individuals more generally when facing lifestyle changes or other life challenges. Having been demonstrated to be associated with changes in people's perception of their well-being in terms of higher psychological health scores on the WHOQOL-BREF, the experience of feedback may have potential to act as a catalyst for many individuals to review their plans and expectations and may thus support improvements in wellbeing.

8.8 Conclusion

In November 2010, the UK Government launched a Public Health White Paper for consultation, entitled "Healthy Lives, Healthy People" (Department of Health, 2010). This was followed in February 2011 with a new mental health strategy: "No Health Without Mental Health" (Department of Health, 2011). Both documents set out the UK Government's current strategy to reduce health inequalities and to improve both the physical and mental health of UK citizens. Also in 2010, the UK's Office for National Statistics (ONS) launched its "Measuring National Wellbeing" programme, with the aim of developing National Statistics to not only measure standards of living, but also QoL. These recent initiatives are all evidence of an increasing focus on the importance of wellbeing and the impact it has in broader economic terms. With the prevailing focus on supporting and improving wellbeing, any methodologies that can improve subjective QoL are timely.

This research programme was based on the underlying premise that subjective ratings of QoL could be used in ways that might have positive consequences for individuals' wellbeing. Receiving guided individualised feedback on core QoL and the importance attributed to its various aspects was demonstrated to be associated with improved scores relating to subjective judgements of psychological health. With a little further development work, the administration of QoL feedback using the WHOQOL may prove to be a valuable and flexible tool for the future benefit of a variety of individuals and in a multitude of settings.

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Appendices

Appendix A Study 1 Task 3, goal booklet

This study has been reviewed and will be supervised by Professor Suzanne Skevington of the World Health Organisation Quality of Life Centre at the University of Bath. To protect your safety, rights, wellbeing and dignity, this study has also been reviewed, and been passed, by an independent University of Bath Research Ethics Committee. If you have any concern or complaint about any aspect of this study, we will do our best to answer your questions

If you have any questions at all about this study, please contact

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Thank you for taking part in this study.

Please use this space for any further comments:

Name:

Participant no.....

Today's date:.....


**USING QUALITY OF LIFE INFORMATION
TO PROMOTE WELLBEING**

My goal booklet


Page 1: My full list of goals

Pages 3 - 10: My goal records

Page 11: Contact details at the University
 Of Bath

 UNIVERSITY OF
BATH

11

 My full list of goals:

On or about, please answer the questions below:

Have I been able to do this? YES / NO / PARTLY

Did I do exactly as agreed? YES / NO / PARTLY

IF NO, OR PARTLY, TO EITHER OF THESE QUESTIONS:

What (if anything) did I do?

When did I do it?

Where did I do it?

What (if anything) do I still intend to do?


When do I plan to do this?

Please explain your reasons or make any comments here:

1

10


Appendix Aii Study 1 Task 3, goal booklet

 GOAL NUMBER 4		Importance 1 - 5	Ease or difficulty 1 - 5	Will you be able to start this in the short (S), medium (M), or long (L) term?								
My goal is _____												
How will I do this?												
To do this I will: _____												

When will I do this – date and time?												
On _____ at _____												
Where will I do this?												
at _____												
How confident am I that I will be able to do this?												
Not at all Confident	Totally confident											
1	2	3	4	5	6	7	8	9	10	1 = very important 5 = not at all important	1 = very easy 3 = neither easy nor difficult 5 = very difficult	S = within the next 2 weeks M = within the next 3 months L = more than 3 months

9


2


 GOAL NUMBER 1		On or about, please answer the questions below:								
My goal is _____		Have I been able to do this? YES / NO / PARTLY								
How will I do this?		Did I do exactly as agreed? YES / NO / PARTLY								
To do this I will: _____		IF NO, OR PARTLY, TO EITHER OF THESE QUESTIONS:								
_____		What (if anything) did I do? _____								
When will I do this – date and time?		When did I do it? _____								
On _____ at _____		Where did I do it? _____								
Where will I do this?		What (if anything) do I still intend to do? _____								
at _____		When do I plan to do this? _____								
How confident am I that I will be able to do this?		Please explain your reasons or make any comments here: _____ _____ _____								
Not at all Confident	Totally confident									
1	2	3	4	5	6	7	8	9	10	

3

8

Appendix Aiii Study 1 Task 3, goal booklet

<div style="display: flex; align-items: center; margin-bottom: 10px;">  <div> <p>GOAL NUMBER 3</p> </div> </div> <p>My goal is _____</p> <p>How will I do this?</p> <p>To do this I will: _____</p> <p>_____</p> <p>When will I do this – date and time?</p> <p>On _____ at _____</p> <p>Where will I do this?</p> <p>at _____</p> <p>How confident am I that I will be able to do this?</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: left;">Not at all Confident</td> <td style="text-align: right;">Totally confident</td> </tr> <tr> <td style="text-align: center;">1 2 3 4 5 6 7 8 9 10</td> <td></td> </tr> </table> <p style="text-align: center; margin-top: 20px;">7</p>	Not at all Confident	Totally confident	1 2 3 4 5 6 7 8 9 10		<p>On or about _____, please answer the questions below:</p> <p>Have I been able to do this? YES / NO / PARTLY</p> <p>Did I do exactly as agreed? YES / NO / PARTLY</p> <p>IF NO, OR PARTLY, TO EITHER OF THESE QUESTIONS:</p> <p>What (if anything) did I do?</p> <p>_____</p> <p>When did I do it?</p> <p>_____</p> <p>Where did I do it?</p> <p>_____</p> <p>What (if anything) do I still intend to do?</p> <p>_____</p> <p>When do I plan to do this?</p> <p>_____</p> <p>Please explain your reasons or make any comments here:</p> <p>_____</p> <p>_____</p> <p style="text-align: center; margin-top: 20px;">4</p>
Not at all Confident	Totally confident				
1 2 3 4 5 6 7 8 9 10					

<div style="display: flex; align-items: center; margin-bottom: 10px;">  <div> <p>GOAL NUMBER 2</p> </div> </div> <p>My goal is _____</p> <p>How will I do this?</p> <p>To do this I will: _____</p> <p>_____</p> <p>When will I do this – date and time?</p> <p>On _____ at _____</p> <p>Where will I do this?</p> <p>at _____</p> <p>How confident am I that I will be able to do this?</p> <table style="width: 100%; border: none;"> <tr> <td style="text-align: left;">Not at all Confident</td> <td style="text-align: right;">Totally confident</td> </tr> <tr> <td style="text-align: center;">1 2 3 4 5 6 7 8 9 10</td> <td></td> </tr> </table> <p style="text-align: center; margin-top: 20px;">5</p>	Not at all Confident	Totally confident	1 2 3 4 5 6 7 8 9 10		<p>On or about _____, please answer the questions below:</p> <p>Have I been able to do this? YES / NO / PARTLY</p> <p>Did I do exactly as agreed? YES / NO / PARTLY</p> <p>IF NO, OR PARTLY, TO EITHER OF THESE QUESTIONS:</p> <p>What (if anything) did I do?</p> <p>_____</p> <p>When did I do it?</p> <p>_____</p> <p>Where did I do it?</p> <p>_____</p> <p>What (if anything) do I still intend to do?</p> <p>_____</p> <p>When do I plan to do this?</p> <p>_____</p> <p>Please explain your reasons or make any comments here:</p> <p>_____</p> <p>_____</p> <p style="text-align: center; margin-top: 20px;">6</p>
Not at all Confident	Totally confident				
1 2 3 4 5 6 7 8 9 10					

Appendix B Study 1 Participant Information Sheet



WHO Field Centre
for the study of quality of life



6th August, 2009

PARTICIPANT INFORMATION SHEET

**USING QUALITY OF LIFE INFORMATION
TO PROMOTE WELLBEING**

We would like to invite you to take part in a research study on using quality of life information to promote wellbeing. Before you decide you need to understand why the research is being done and what it would involve for you. Please read the following information and ask if there is anything that is not clear or if you would like to know more. Please take your time to decide whether or not you wish to take part.

Kind regards
Alison Llewellyn BA, BSc, MSc (Researcher)

What is the purpose of the study?

Many researchers have looked at how different groups of people rate their quality of life. This information has often been used to get a picture of the wellbeing of large groups of people and to help improve health care.

However, not many studies have considered how people might use quality of life information themselves, to help them with the challenges they face in life.

We are carrying out this project as part of ongoing research at the World Health Organisation Centre for the Study of Quality of Life at the University of Bath. This study seeks to understand how giving people information about quality of life might affect their goals and feelings. At this time, we are trying to develop the best ways of doing this, and are testing out a number of activities that we might want to include. We are particularly interested in older adults and the effects of ageing on wellbeing. We are asking for help from people aged 50 and over and would be very pleased if you would like to participate.

Do I have to take part?

It is up to you to decide. This information sheet will describe the study and we would like you to read through, then ask any questions you may have. We shall ask you to sign a consent form if you agree to take part. After that, you are free to withdraw at any time, without giving any reason.

What will happen to me if I take part?

Once you have agreed to take part, you will firstly be asked to complete a consent form which you should sign and return if you are happy to take part in this study.

You will then be asked to complete one or more activities. These might be completing a quality of life questionnaire and having feedback on the results; thinking and writing about quality of life generally; identifying personal goals or describing how you would go about achieving your short term goals.

After this, you will be asked to answer a questionnaire asking you about your views on what you were required to do.

What are the possible disadvantages and risks of taking part?

Thinking about your quality of life or your goals in life may raise issues for you that you find difficult. If you feel in any way uncomfortable with any part of the study, you are free to withdraw from the study at any time without having to give any reason. If you experience any emotional distress as a result of the project, it may be useful to speak to your GP or to contact Age Concern on 0800 00 99 66.

What are the possible benefits of taking part?

We cannot promise the study will help you individually but you may find at the end that you have a better understanding of your views about your own quality of life or your goals in life. The overall information from this study will be used to design a way of providing better support to people who are adjusting to changes in their lives.

Appendix Bii Study 1 Participant Information Sheet

Will my taking part in the study be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in complete confidence and kept securely. Your data will be given a unique number so that you will not be able to be identified. It will only be used by researchers at the World Health Organisation Quality of Life Centre at the University of Bath and will not be passed on to anyone else. The information you give will not affect any care or services you currently receive.

If you decide to withdraw from the study we will ask for your permission for us to use any data you have already given us.

What will happen to the results of the research study?

The broad scientific results of the study will be written up to form part of a doctoral thesis. The study may also be presented at academic conferences and published in a suitable academic journal. However, you will not be personally identified in any presentation or published document.

If, after the study, you would like us to give you further information on the overall results, we will be happy to do this by sending you a summary of what we find.

Who has reviewed the study?

This study has been reviewed and will be supervised by Professor Suzanne Skevington of the World Health Organisation Quality of Life Centre at the University of Bath. To protect your safety, rights, wellbeing and dignity, this study has also been reviewed, and been passed, by an independent University of Bath Research Ethics Committee. If you have any concern or complaint about any aspect of this study, we will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the Department of Psychology (2 South), University of Bath, BATH, BA2 7AY.

If you have any questions at any time, before, or after deciding whether you want to take part in this study, you are very welcome to contact Alison Llewellyn on 01225 383407 or by email on a.m.llewellyn@bath.ac.uk

6th August, 2009



WHO Field Centre
for the study of quality of life



6th August, 2009

CONSENT FORM

**USING QUALITY OF LIFE INFORMATION
TO PROMOTE WELLBEING**

Researcher: Alison Llewellyn

Once you have read the Participant Information Sheet *AND IF* you have decided that you would like to take part in the above study, please tick the boxes below:

1. I confirm that I have read and understand the information sheet dated 6th August 2009 for the above study. ☐
2. I have had the opportunity to ask questions and have had these answered satisfactorily. ☐
3. I understand that my participation is completely voluntary and that I am free to withdraw at any time without giving any reason, without my medical or other care or legal rights being affected. ☐
4. I give permission for any information I give to be securely stored at the University of Bath for 5 years after the study is completed. ☐
5. I agree to the study report quoting my verbal or written comments directly, as long as any quotations used are made anonymous. ☐
6. I agree to take part in the above study. ☐

Name of Participant

Date

Signature


Name of Researcher

Date

Signature

Appendix D Study 1 Evaluation of Task 1: Free-form writing about QoL

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Evaluation of quality life general discussion

1. How interested were you in the general information the researcher gave you about quality of life?

Please tick on the scale below where 1 is not at all interested and 7 is very interested.

Very uninterested	Mostly uninterested	Fairly uninterested	Neither interested nor uninterested	Fairly interested	Mostly interested	Very interested
1	2	3	4	5	6	7

Please tell us why:

2. How did you find the information the researcher gave you about quality of life?

Please tick on the scale below where 1 is too short and 5 is too long.

Very much too short	A little too short	About right	A little too long	Very much too long
1	2	3	4	5

Please tell us why:


3. How helpful did you find the information in thinking about your own quality of life?

Please tick on the scale below where 1 is not at all helpful and 7 is very helpful.


Very Unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

Please tell us why:

1



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4. Was there anything relating to the information we could have done differently? YES / NO

If yes, please tell us what would have improved this. We would like to know about all the ideas you have:

Thank you for your help.

Appendix E Study 1 Evaluation of Task 2: written instructions for feedback

 WHO Field Centre <i>for the study of quality of life</i>	 UNIVERSITY OF BATH
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Evaluation of written feedback on WHOQOL-BREF

1. How interested were you in the feedback you were given on your quality of life?
Please tick on the scale below where 1 is not at all interested and 7 is very interested.

Very uninterested	Mostly uninterested	Fairly disinterested	Neither interested nor uninterested	Fairly interested	Mostly interested	Very interested
1	2	3	4	5	6	7

Please tell us why:

2. How helpful did you find it to have the instructions on how to read the graphs?
Please tick on the scale below where 1 is not at all helpful and 7 is very helpful.

Very Unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

Please tell us why:


3. Was there anything relating to the instructions we could have done differently? YES / NO

(Please think about the instructions, not the graphs themselves – these will be asked about in a later questionnaire.)


If yes, please tell us what would have improved this. We would like to know about all the ideas you have:

Thank you for your help.

Appendix F Study 1 Evaluation of Task 2: verbal feedback



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Evaluation of verbal feedback on WHOQOL-BREF

1. How interested were you in the feedback you were given on your quality of life?
Please tick on the scale below where 1 is not at all interested and 7 is very interested.

Very uninterested	Mostly uninterested	Fairly uninterested	Neither interested nor uninterested	Fairly interested	Mostly interested	Very interested
1	2	3	4	5	6	7

Please tell us why:

2. How helpful did you find it to have someone explain your results to you?
Please tick on the scale below where 1 is not at all helpful and 7 is very helpful.

Very Unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7


Please tell us why:

3. How did you find the conversation you had with the researcher about your results?
Please tick on the scale below where 1 is too short and 5 is too long.


Very short	A little short	About right	A little long	Very long
1	2	3	4	5

Please tell us why:

1



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4. Was there anything relating to the help you were given to understand the graphs that we could have done differently?
YES / NO


If yes, please tell us what would have improved this. We would like to know about all the ideas you have:

Thank you for your help.


2

Appendix G Study 1 Evaluation of Task 2: graphical summary profile

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Evaluation of WHOQOL-BREF graphs

1. How useful were the graphs to you in helping you to understand your quality of life?
Please tick on the scale below where 1 is not at all helpful and 7 is very helpful.

Very Unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

2. How helpful would it be to have the graphs to take away?
Please tick on the scale below where 1 is not at all helpful and 7 is very helpful.

Very Unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly helpful	Mostly Helpful	Very helpful
1	2	3	4	5	6	7

3. Will you think about the graphs after today? (Please circle) YES / NO / MAYBE


4. Will you look at the graphs after you get home? (Please circle) YES / NO / MAYBE

5. Will you discuss the graphs with anyone else? (Please circle) YES / NO / MAYBE


If yes or maybe, who do you think you will discuss them with?

Which aspects will you discuss?

1



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Why these aspects?

6. Have the graphs affected the way you think about your quality of life in any way? YES / NO

If yes, in what ways?


7. How helpful were the graphs in helping you to think about and set your goals?
Please indicate on the scale below where 1 is not at all helpful and 7 is very helpful.

Very unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly Helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7


Thank you for your help.

2

Appendix H Study 1 Evaluation of Task 3: goals elicitation and assessment



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Evaluation of goals elicitation and assessment task

1. Please can you tell me your thoughts about what you were asked to do to identify your list of goals?

2. How clear were the instructions you were given?
Please tick on the scale below where 1 is very unclear and 7 is very clear.

Very unclear	Mostly unclear	Fairly unclear	Neither clear nor unclear	Fairly clear	Mostly clear	Very clear
1	2	3	4	5	6	7


Could we make any changes to improve this?

3. How easy was it to think of your list of goals?
Please tick on the scale below where 1 is very difficult and 7 is very easy.


Very difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

Could we make any changes to improve this?

1



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4. What did you think about the card sorting task?
Please tick on the scale below where 1 is very unhelpful and 7 is very helpful.

Very unhelpful	Mostly unhelpful	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

Could we make any changes to improve this?

5. How easy was it to think of importance of your goals?
Please tick on the scale below where 1 is very difficult and 7 is very easy.

Very difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7


Could we make any changes to improve this?

6. How easy was it to think of timescales for your goals?
Please tick on the scale below where 1 is very difficult and 7 is very easy.


Very difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

Could we make any changes to improve this?

2



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7. Was there anything you didn't understand? If yes, what:

8. Was there anything else we could have done differently? If yes, what:


Thank you for your help.

3

Appendix I Study 1 Evaluation of Task 3: goals booklet



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Evaluation of goal booklet

1. How easy did you find it to think of the action you would take for each goal?
Please tick on the scale below where 1 is very difficult and 7 is very easy.

Very Difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

2. How easy did you find it to think of when and where you would do each action?
Please tick on the scale below where 1 is very difficult and 7 is very easy.

Very Difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

3. How easy did you find it to complete the confidence scale?
Please tick on the scale below where 1 is very difficult and 7 is very easy.

Very Difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

4. Did you manage to complete all the pages in the goals booklet? YES / NO

If not, why not?

5. How easy did you find it to understand the goal booklet overall? Please tick on the scale below where 1 is very difficult and 7 is very easy.

Very Difficult	Mostly difficult	Fairly difficult	Neither easy nor difficult	Fairly easy	Mostly easy	Very easy
1	2	3	4	5	6	7

P.T.O.



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6. Is there anything we could have done to make the goal booklet better? YES / NO

If yes, what?


7. On a scale of 1 to 7 where 1 is not at all helpful and 7 is very helpful, how helpful did you find the goal booklet is in helping you to work on your goals?

Very unhelpful	Mostly unhelpful	Fairly unhelpful	Neither helpful nor unhelpful	Fairly Helpful	Mostly helpful	Very helpful
1	2	3	4	5	6	7

8. Can you think of anything else which might have helped you to make this easier for you? YES / NO

If yes, what?

Thank you for your help.

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4. What do you think was least useful about what you were asked to do?

Why?

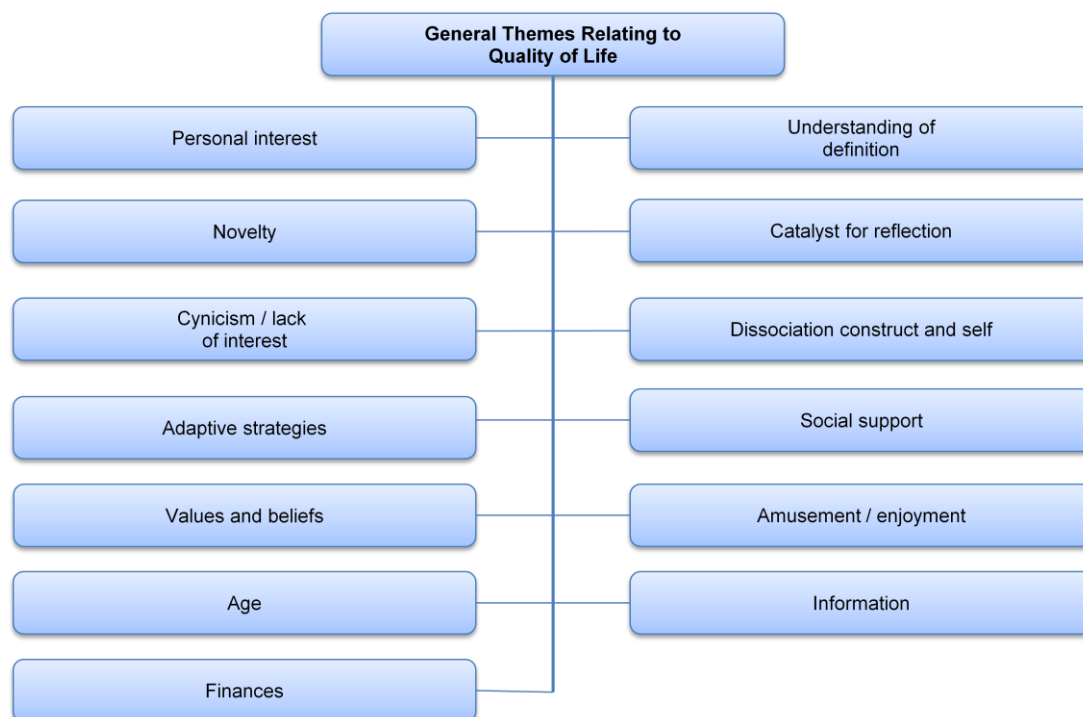
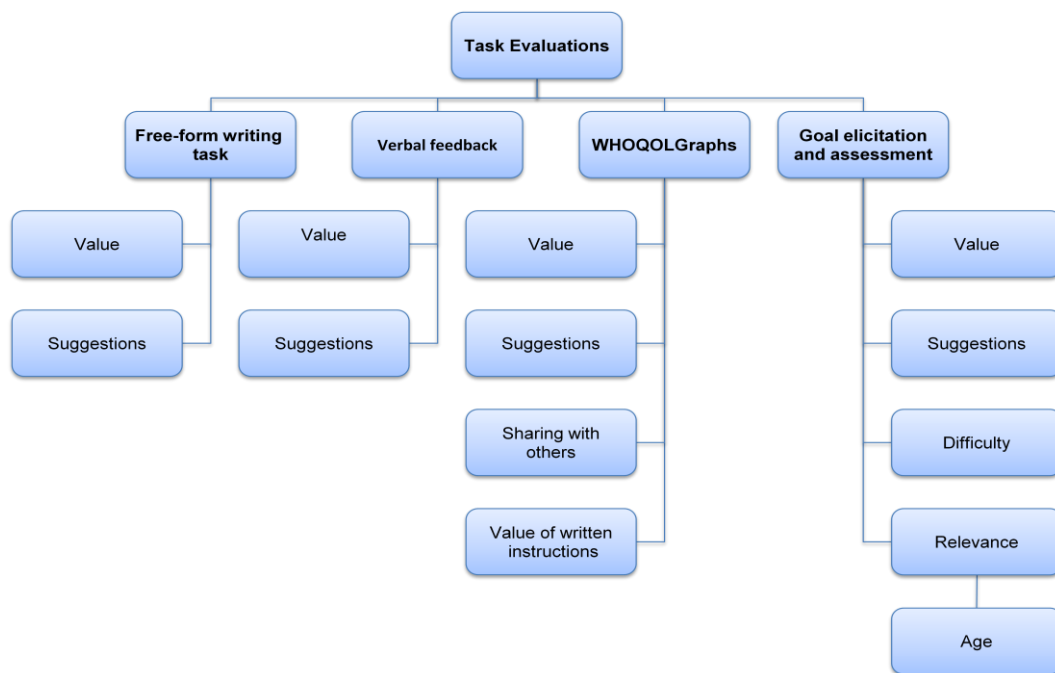
5. What do you think was most useful about what you were asked to do?

Why?

6. Is there anything else you would like to tell me that has not already been covered?

Thank you for your help.

Appendix K Study 1 Taxonomy of Coding for Qualitative Analysis



Appendix L Study 1 Task evaluation comments, transcribed by theme

Task Evaluation Themes	Comment	Task and question
Free-form writing task: Value	<i>Within its limitations... it was adequate. (Participant 2)</i> <i>No-one needs information overload. (Participant 9)</i> <i>Generally good. (Participant 10)</i> <i>[The information] Indicated areas which needed to be considered. (Participant 8)</i> <i>It was helpful in seeing the information written down. (Participant 10)</i> <i>I disliked the thought of writing an essay about myself. (Participant 3)</i>	QoL writing task: information given QoL writing task: information given QoL writing task: information given QoL writing task and thinking about own QoL QoL writing task and thinking about own QoL QoL writing task suggested improvements
Free-form writing task: suggestions	<i>The information was not really new, but I needed something to guide my answer. (Participant 6)</i> <i>Needed to be divided into topics. (Participant 3)</i> <i>I need specific questions to answer and perhaps the interviewer evaluate the answer as they can make comparisons. (Participant 3)</i> <i>Perhaps it would be a good idea to have a section on religious belief. Many of us find that our beliefs or lack of beliefs are the most important factors in how we live our lives. (Participant 2)</i> <i>Specific headings and perhaps examples. (Participant 3)</i> <i>Provide a checklist. (Participant 8)</i> <i>It's much easier to tick boxes. Headings would help but it's difficult to do. (Participant 3)</i> <i>It would be useful to have a checklist. It's difficult otherwise, when you haven't really thought about quality of life before. (Participant 8)</i>	QoL writing task: interest in QoL information QoL writing task: information given QoL writing task and thinking about own QoL QoL writing task suggested improvements QoL writing task suggested improvements QoL writing task suggested improvements General comments General comments

Appendix Lii Study 1 Task evaluation comments, transcribed by theme

Theme	Comment	Task & question
Verbal feedback: value	<i>The interview clarified my own perspective of quality of life and necessity of growing old “gracefully”. (Participant 4)</i>	1:1 feedback interest
	<i>Able to evaluate the graphs. (Participant 8)</i>	1:1 feedback interest
	<i>Useful information. (Participant 1)</i>	Helpfulness of 1:1 explanation
	<i>Didn’t really need any help. (Participant 2)</i>	Helpfulness of 1:1 explanation
	<i>I kept having to be reminded and remind myself the difference between red triangle and blue bars. (Participant 3)</i>	Helpfulness of 1:1 explanation
	<i>The explanations all mostly self evident as far as this writer is concerned. (Participant 4)</i>	Helpfulness of 1:1 explanation
	<i>The resulting discussion. (Participant 9)</i>	Helpfulness of 1:1 explanation
	<i>Useful information. (Participant 1)</i>	How participants found the 1:1 conversation
	<i>Pleasant in a quiet sort of way. Not boring. (Participant 2)</i>	How participants found the 1:1 conversation
	<i>I find it easier to talk and answer questions than write descriptions. (Participant 3)</i>	How participants found the 1:1 conversation
	<i>Being able to say something in response is nice. (Participant 6)</i>	How participants found the 1:1 conversation
	<i>Because as a ½ Celt I can talk for ever. (Participant 9)</i>	How participants found the 1:1 conversation
	<i>Good. (Participant 10)</i>	How participants found the 1:1 conversation
	<i>Talk to [the researcher]. (Participant 7)</i>	Most useful aspect of study
	<i>I preferred the one-to-one feedback because I like to be able to ask questions. (Participant 1)</i>	General comments
	<i>Asking leading questions is useful – exploring it in more depth. It’s good to explore. (Participant 3)</i>	General comments
	<i>I find it far too introspective. (Participant 7)</i>	General comments

Appendix Liii Study 1 Task evaluation comments, transcribed by theme

Theme	Comment	Task & question
WHOQOL Graphs: value	<p><i>Not as good as verbal. (Participant 1)</i></p> <p><i>I am obviously interested in anything about myself, but I did not tick 7 because it was only telling me what I had already put on the forms, albeit in a slightly different form. (Participant 6)</i></p> <p><i>Information very clear. (Participant 10)</i></p> <p><i>Quite amusing to see my answers put into graph form. (Participant 2)</i></p> <p><i>Interested to see how my answers were interpreted. (Participant 3)</i></p> <p><i>The graphs are helpful because they give an idea of my ambitions and achievements. Gives a focus. (Participant 1)</i></p>	<p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>General comments</p>
WHOQOL Graphs: suggestions	<p><i>Too wordy. (Participant 3)</i></p> <p><i>I suppose it could have said precisely how the values were calculated, but I do not think this would have been appropriate here. (Participant 6)</i></p> <p><i>They could have been more concise. (Participant 8)</i></p> <p><i>I don't understand the relationship between the triangles and the bars. There's possibly something needed on the heading as to which is quality of life and which is importance. (Participant 3)</i></p>	<p>WHOQOL Graphs suggested improvements</p> <p>WHOQOL Graphs suggested improvements</p> <p>WHOQOL Graphs suggested improvements</p> <p>General comments</p>

Appendix Liv Study 1 Task evaluation comments, transcribed by theme

Theme	Comment	Task & question
WHOQOL Graphs: Sharing with others	<p><i>My wife and possibly my two daughters. (Participant 1)</i></p> <p><i>Close friends with a teaching / nursing / medical background – not family. (Participant 3)</i></p> <p><i>My wife. (Participant 7)</i></p> <p><i>A friend. (Participant 8)</i></p> <p><i>My daughters. (Participant 9)</i></p> <p><i>Friends and family. (Participant 10)</i></p> <p><i>Most I expect. (Participant 1)</i></p> <p><i>The structure of the questionnaire and its relevance. (Participant 3)</i></p> <p><i>My perception of the importance of the results. (Participant 7)</i></p> <p><i>Positive and negative aspects. (Participant 8)</i></p> <p><i>The whole lot. (Participant 9)</i></p> <p><i>Mostly all the graphs given to me. (Participant 10)</i></p> <p><i>My wife will probably be more interested than I am. (Participant 7)</i></p> <p><i>To understand the importance of my attitude to areas of my life. (Participant 8)</i></p> <p><i>Both my daughters are interested in my health and welfare. (Participant 9)</i></p>	<p>WHOQOL Graphs intent to share with WHOQOL Graphs intent to share with</p> <p>WHOQOL Graphs intent to share with WHOQOL Graphs intent to share with WHOQOL Graphs intent to share with WHOQOL Graphs intent to share with WHOQOL Graphs – aspects intended to share WHOQOL Graphs – aspects intended to share WHOQOL Graphs – aspects intended to share WHOQOL Graphs – aspects intended to share WHOQOL Graphs – aspects intended to share WHOQOL Graphs – aspects intended to share WHOQOL Graphs – why these aspects WHOQOL Graphs – why these aspects WHOQOL Graphs – why these aspects</p>
Written instructions: Value	<p><i>Not as good as verbal. (Participant 1)</i></p> <p><i>I am obviously interested in anything about myself, but I did not tick 7 because it was only telling me what I had already put on the forms, albeit in a slightly different form. (Participant 6)</i></p> <p><i>Information very clear. (Participant 10)</i></p> <p><i>Did not really need any help, but if I had, it would have been very helpful. (Participant 2)</i></p> <p><i>It was rather obvious. (Participant 6)</i></p> <p><i>Like exams one should always read the instructions even if you think you know the answers! (Participant 9)</i></p>	<p>Written instructions: interest; helpfulness Written instructions: interest</p> <p>Written instructions: interest Written instructions: helpfulness</p> <p>Written instructions: helpfulness Written instructions: helpfulness</p>

Appendix Lvi Study 1 Task evaluation comments, transcribed by theme

Theme	Comment	Task & question
Goal elicitation and assessment: relevance	<i>I need to consider setting goals in my life. (Participant 8)</i>	Effect of participation on QoL thinking
	<i>I'm not sure if I really have any [goals]. [I] prefer to take one day at a time and rise to a challenge if it occurs. (Participant 3)</i>	Least useful aspect of study – why
	<i>Older adults guard against having goals because they may not be able to achieve them. (Participant 3)</i>	General comments
	<i>Perhaps because of the things that have happened to me, I don't set goals really. (Participant 3)</i>	General comments
	<i>It's awful I don't have any goals but perhaps I should. I had goals when I was younger but not any more. I need to think about it more I suppose. (Participant 8)</i>	General comments
	<i>I really need to think about writing that book about all the stories I tell my grandchildren. (Participant 8)</i>	General comments
	<i>In this financial climate you're just able to survive each day. (Participant 10)</i>	General comments
	<i>My goal is really to try to sustain my way of life. It's about being able to retire and still do things. It all comes down to finances. (Participant 10)</i>	General comments
	<i>If people are in this financial situation they have to give up goals. (Participant 10)</i>	General comments
	<i>I suppose my goal is to stay healthy and fit because I've got no-one to support me if I'm ill...When you're younger, it's different altogether. (Participant 10)</i>	General comments Goal instructions
	<i>But at my age (75+) I have no aims but to stay alive. (Participant 7)</i>	Goal instructions
	<i>Nothing really matters to me any more. (Participant 7)</i>	General comments

Appendix Lvii Study 1 Task evaluation comments, transcribed by theme

Goal elicitation and assessment: age	<i>But at my age (75+) I have no aims but to stay alive. (Participant 7)</i> <i>Take account of my age. (Participant 7)</i> <i>Ask questions relevant to my age. (Participant 7)</i> <i>Older adults guard against having goals because they may not be able to achieve them. (Participant 3)</i> <i>My only goal is to live to 80. (Participant 7)</i> <i>I had goals when I was younger but not any more. I need to think about it more I suppose. (Participant 8)</i> <i>I think as you get older you have less [sic] goals. (Participant 10)</i> <i>I suppose my goal is to stay healthy and fit because I've got no-one to support me if I'm ill...When you're younger, it's different altogether. (Participant 10)</i>	Goal instructions Thinking of goals – suggestions Goal elicitation tasks – suggestions General comments General comments General comments General comments General comments
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Appendix M Study 1 General themes evidenced in participants' comments

Theme	Comment	Task & question
Personal interest	<p><i>Just find it interesting. (Participant 1)</i></p> <p><i>To see what research would reveal in reference to a “normal” person and everyday life. (Participant 4)</i></p> <p><i>It is always good to reflect on one’s blessings. (Participant 9)</i></p> <p><i>Interested to see how my answers were interpreted. (Participant 3)</i></p> <p><i>I am obviously interested in anything about myself, but I did not tick 7 because it was only telling me what I had already put on the forms, albeit in a slightly different form. (Participant 6)</i></p> <p><i>It is always interesting to get feedback... (Participant 9)</i></p> <p><i>It was interesting to see the information put down on paper. (Participant 10)</i></p> <p><i>Useful information. (Participant 1)</i></p> <p><i>Same answer as for written feedback. (Participant 6) (Written feedback answer - I am obviously interested in anything about myself, but I did not tick 7 because it was only telling me what I had already put on the forms, albeit in a slightly different form)</i></p> <p><i>It was interesting to see your personal scale. (Participant 10)</i></p>	<p>QoL writing task: interest in QoL information</p> <p>QoL writing task: interest in QoL information</p> <p>QoL writing task and thinking about own QoL</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs interest in feedback</p> <p>WHOQOL Graphs helpfulness of instructions</p> <p>1:1 feedback interest</p> <p>1:1 feedback interest</p> <p>1:1 feedback interest</p>
Understanding definition of QoL	<p><i>I think that “quality of life” needs more definition than self-centred goals and feelings. One’s general philosophy is the most important thing. (Participant 2)</i></p> <p><i>I don’t know how to define “quality of life”. (Participant 3)</i></p> <p><i>I’m not sure how quality of life applies. (Participant 2)</i></p> <p><i>[Quality of life is] an attitude rather than a reality. (Participant 3)</i></p> <p><i>I am of the opinion that to a large extent life is what you make it – though for many people practical help might be a necessity. (Participant 4)</i></p> <p><i>I have great trouble with the concept, or the phrase, “the meaning of life”. (Participant 6)</i></p>	<p>QoL writing task: interest in QoL information</p> <p>QoL writing task: interest in QoL information</p> <p>General comments</p> <p>General comments</p> <p>General comments</p> <p>General comments</p>

Appendix Mii Study 1 General themes evidenced in participants' comments

Novelty & curiosity	<p><i>Something I hadn't considered before. (Participant 8)</i></p> <p><i>Because I am basically a very curious (interested) person. (Participant 9)</i></p> <p><i>It is always interesting to get feedback even if some of it is a little surprising. (Participant 9)</i></p> <p><i>I've not analysed my quality of life before so it me think. (Participant 3)</i></p> <p><i>Not really analysed what is important to me before. (Participant 3)</i></p>	<p>QoL writing task: interest in QoL information</p> <p>QoL writing task: interest in QoL information</p> <p>WHOQOL Graphs interest in feedback</p> <p>1:1 feedback interest</p> <p>Effect of participation on QoL thinking</p>
Catalyst for reflection	<p><i>It has started me thinking of my quality of life at present. (Participant 10)</i></p> <p><i>It illustrated aspects of my life I hadn't considered. (Participant 8)</i></p> <p><i>I've not analysed my quality of life before so it me think. (Participant 3)</i></p> <p><i>Made me realise how lucky I am. (Participant 1)</i></p> <p><i>The ways in which I value aspects of my life. (Participant 8)</i></p> <p><i>Contemplation of the answers. (Participant 7)</i></p> <p><i>I've had great change in my life – quite dramatic. It was only when I was divorced that I really ever thought about quality of life. (Participant 8)</i></p>	<p>QoL writing task: interest in QoL information</p> <p>WHOQOL Graphs interest in feedback</p> <p>1:1 feedback interest</p> <p>Effect of WHOQOL Graphs on thinking about QoL</p> <p>Effect of WHOQOL Graphs on thinking about QoL</p> <p>Least useful aspect of study</p> <p>General comments</p>
Cynicism / lack of interest	<p><i>I understood what the research was trying to understand – although a trifle cynical in what it could produce! (Participant 4)</i></p> <p><i>It is not of interest to me. (Participant 7)</i></p> <p><i>It is simply that the topic does not interest me. (Participant 7)</i></p> <p><i>It's about as interesting as a game of Scrabble. (I quite like Scrabble, but it's not important.) (Participant 2)</i></p> <p><i>It is not a topic that interests me. (Participant 7)</i></p> <p><i>I am not interested in the topic. (Participant 7)</i></p> <p><i>I'm quite sceptical about these things. I'm not sure how quality of life applies. (Participant 2)</i></p> <p><i>It seems ungrateful I have a good quality of life but am not interested. (Participant 7)</i></p> <p><i>I've got to 76. If something happens now, it won't last long. (Participant 7)</i></p>	<p>QoL writing task: information given</p> <p>QoL writing task and thinking about own QoL</p> <p>QoL writing task suggested improvements</p> <p>1:1 feedback interest</p> <p>1:1 feedback interest</p> <p>Least useful aspect of study – why</p> <p>General comments</p> <p>General comments</p> <p>General comments</p>

Appendix Miii Study 1 General themes evidenced in participants' comments

Dissociation construct of QoL and self	<i>I don't think about my quality of life usually. (Participant 2)</i> <i>Sometimes you just can't think about yourself. (Participant 2)</i>	QoL writing task and thinking about own QoL General comments
Adaptive strategies	<i>[I] just get on with living. (Participant 2)</i> <i>It is always good to reflect on one's blessings. (Participant 9)</i> <i>I'm not sure if I really have any [goals]. [I] prefer to take one day at a time and rise to a challenge if it occurs. (Participant 3)</i> <i>It's a personal thing – I cope with life by taking it one day at a time. (Participant 3)</i> <i>What's problematic I've solved, and what I can't solve I accept. (Participant 7)</i> <i>I have strategies for dealing with problems, for example my deafness. I refuse to wear a hearing aid but I use the loop system in the theatre. (Participant 7)</i>	QoL writing task and thinking about own QoL QoL writing task and thinking about own QoL Least useful aspect of study – why General comments General comments General comments
Social support	<i>My pattern of life – including family relations – is well established and without problems. (Participant 4)</i> <i>I suppose my goal is to stay healthy and fit because I've got no-one to support me if I'm ill...When you're younger, it's different altogether. (Participant 10)</i>	QoL writing task and thinking about own QoL General comments
Values and beliefs	<i>Perhaps it would be a good idea to have a section on religious belief. Many of us find that our beliefs or lack of beliefs are the most important factors in how we live our lives. (Participant 2)</i>	QoL writing task suggested improvements
Amusement / Enjoyment	<i>Quite amusing to see my answers put into graph form. (Participant 2)</i> <i>I was amused as this is a questionnaire that sexual health was included – but then I guess most of the age group will have lived through the swinging sixties even if we didn't necessarily participate. (Participant 9)</i> <i>An interesting and enjoyable 2 hours. (Participant 7)</i> <i>She [the researcher] is very nice. (Participant 7)</i>	WHOQOL Graphs interest in feedback WHOQOL Graphs suggested improvements Effect of participation on QoL thinking Most useful aspect of study - why

Appendix Miv Study 1 General themes evidenced in participants' comments

Theme	Comment	Task & question
Age / Ageing	<p><i>The interview clarified my own perspective of quality of life and necessity of growing old “gracefully”. (Participant 4)</i></p> <p><i>But at my age (75+) I have no aims but to stay alive. (Participant 7)</i></p> <p><i>Ask questions relevant to my age. (Participant 7)</i></p> <p><i>Take account of my age. (Participant 7)</i></p> <p><i>My only goal is to live to 80. (Participant 7)</i></p> <p><i>I think as you get older you have less [sic] goals. (Participant 10)</i></p> <p><i>I suppose my goal is to stay healthy and fit because I’ve got no-one to support me if I’m ill... When you’re younger, it’s different altogether. (Participant 10)</i></p>	<p>1:1 feedback interest</p> <p>Goal instructions</p> <p>Goals elicitation and assessment: age</p> <p>Thinking of goals – suggestions</p> <p>General comments</p> <p>General comments</p> <p>General comments</p>
Information	<i>Information is always useful. (Participant 9)</i>	1:1 feedback interest
Finances	<p><i>In this financial climate to you’re just able to survive each day. (Participant 10)</i></p> <p><i>My goal is really to try to sustain my way of life. It’s about being able to retire and still do things. It all comes down to finances. (Participant 10)</i></p> <p><i>If people are in this financial situation they have to give up goals. (Participant 10)</i></p>	<p>General comments</p> <p>General comments</p> <p>General comments</p>

Appendix N Study 2 Recruitment Flyer



WHO Field Centre
for the study of quality of life



**UNIVERSITY OF
BATH**

*WOULD YOU LIKE TO TELL US ABOUT YOUR QUALITY
OF LIFE AND WELLBEING?*

We are conducting research into quality of life for adults. We need volunteers who can help us by thinking about quality of life and by completing some questionnaires.

If you think you might be interested in helping us, please complete the slip below. We will then get in touch to tell you more about the study. Please note, **your personal details will be kept completely confidential.**

You don't have to take part and, even if you express an interest, you are still free to choose whether to participate and can withdraw at any time.

Further information is available from Alison Llewellyn at the University:
email: a.m.llewellyn@bath.ac.uk or tel: 01225 383407 (answerphone).



----- ✂
I would like to find out more about the quality of life study and am
happy for you to contact me.

Name:

Address:.....

.....

Telephone:

Email:

**Send to: Alison Llewellyn, Department of Psychology (2 South),
University of Bath, Claverton Down, BATH. BA2 7AY**

Appendix O Study 2 Participant Information Sheet, Consent Form and Covering Letter

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6th April, 2010

QUALITY OF LIFE AND WELLBEING

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study on quality of life information and wellbeing. Before you decide you need to understand why the research is being done and what it would involve for you. Please read the following information and ask if there is anything that is not clear or if you would like to know more. Please take your time to decide whether or not you wish to take part.

Kind regards
Allison Llewellyn BA, BSc, MSc (Researcher)

What is the purpose of the study?

Many researchers have looked at how different groups of people rate their quality of life. This information has often been used to get a picture of the wellbeing of large groups of people and to help improve health care. However, not many studies have considered how the process of thinking about quality of life might affect individuals' wellbeing.

We are carrying out this project as part of ongoing research at the World Health Organisation Centre for the Study of Quality of Life at the University of Bath. This study seeks to understand how thinking about quality of life might affect our goals and feelings.

Do I have to take part?

It is up to you to decide. This information sheet will describe the study and we would like you to read it through and to ask any questions you need to before you do anything more. Once you are satisfied you still wish to take part you will need to sign and return the enclosed consent form. At any time after that, you are still free to withdraw from the study if you wish, without giving any reason and without your medical or other care or legal rights being affected.

What will happen to me if I take part?

You will then be asked to complete some short questionnaires, asking you about your health, feelings and aspects of your quality of life. This pack will also include a questionnaire about you – age, marital status and such like. Please note, there are no right or wrong answers. You will be provided with a stamped, addressed envelope to return these to the University. One week later you will be asked to complete a second, shorter pack, with some final questions about how you felt about the study and what you were asked to do. It is intended that you will complete this pack exactly one week after the first set of questionnaires.

Please turn over

What are the possible benefits of taking part?

We cannot promise the study will help you individually but you may find at the end that you will know more about quality of life. The overall information from this study will be used to design a way of providing better support to people who are adjusting to changes in their lives.

What are the possible disadvantages and risks of taking part?

Thinking about your quality of life or your goals and feelings may raise issues for you that you find difficult. If you feel in any way uncomfortable with any part of the study, you are free not to answer or to withdraw from the study at any time without having to give any reason. If you experience any emotional distress as a result of the project, it may be useful to speak to your GP or to a counsellor.

Will my taking part in the study be kept confidential?

Yes. We will follow strict ethical and legal practice and all information about you will be handled in complete confidence and kept securely. Your data will be given a unique number so that you will not be able to be identified. It will only be used by researchers at the World Health Organisation Quality of Life Centre at the University of Bath and will not be passed on to anyone else. The information you give will not affect any care or services you currently receive.

If you decide to withdraw from the study we will ask for your permission for us to use any data you have already given us.

What will happen to the results of the research study?

The broad scientific results of the study will be written up to form part of a doctoral thesis. The study may also be presented at academic conferences and published in a suitable academic journal. However, you will not be personally identified in any presentation or published document.

If, after the study, you would like us to give you further information on the overall results, we will be happy to do this by sending you a summary of what we find.

Who has reviewed the study?


This study has been reviewed and will be supervised by Professor Suzanne Skevington of the World Health Organisation Quality of Life Centre at the University of Bath. To protect your safety, rights, wellbeing and dignity, this study has also been reviewed, and been passed, by an independent University of Bath Research Ethics Committee. If you have any concern or complaint about any aspect of this study, we will do our best to answer your questions. If you remain unhappy and wish to complain formally, you can do this by contacting Professor Skevington at the Department of Psychology (2 South), University of Bath, BATH, BA2 7AY.

If you have any questions at any time, before, or after deciding whether you want to take part in this study, you are very welcome to contact


*Allison Llewellyn on
01225 383407 or by email on a.m.llewellyn@bath.ac.uk*

Appendix Oii Study 2 Participant Information Sheet, Consent Form and Covering Letter

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WHO Field Centre
for the study of quality of life



UNIVERSITY OF
BATH
Study 2
6th April 2010

CONSENT FORM

QUALITY OF LIFE INFORMATION AND WELLBEING

Researcher: Alison Llewellyn

Once you have read the Participant Information Sheet *AND IF* you have decided that you would like to take part in the above study, please tick the boxes below:

1. I confirm that I have read and understand the information sheet dated 6th April 2010 for the above study. ☐
2. I have had the opportunity to ask questions and have had these answered satisfactorily. ☐
3. I understand that my participation is completely voluntary and that I am free to withdraw at any time without giving any reason, without my medical or other care or legal rights being affected. ☐
4. I give permission for any information I give to be securely stored at the University of Bath for 5 years after the study is completed. ☐
5. I agree to the study report quoting my verbal or written comments directly, as long as any quotations used are made anonymous. ☐
6. I agree to take part in the above study. ☐

Name of Participant


Name of Researcher

Date


Date

Signature

Signature



WHO Field Centre
for the study of quality of life



UNIVERSITY OF
BATH

Department of Psychology
Bath BA2 7AY · United Kingdom
Telephone 01225 383843
Facsimile 01225 386752

April, 2010

Dear

Quality of life information and wellbeing study

Thank you for showing interest in this research. We are carrying out this study as part of ongoing research programme at the World Health Organisation Centre for the Study of Quality of Life at the University of Bath. To help us with this we will need people to complete a series of questionnaires and/or paper tasks.

Enclosed with this letter you will find a pack of questionnaires. Before you open the pack, please first carefully read the attached participant information sheet which will tell you more about the study. If you have any questions, please contact me by email on a.m.llewellyn@bath.ac.uk or you can leave me a message on my answerphone on 01225 383407 and I will call you back as soon as possible. You are completely free to choose whether to participate and can withdraw at any time. If you decide not to take part, I should be grateful if you would let me know.

Once you have read the participant information sheet, and **if** you have decided to continue, please complete the documents **in the following order**:

1. Consent form
2. Questionnaire Booklet 1
3. Task Sheets
4. Questionnaire Booklet 2

Please note there are no right and wrong answers.

Please return all documents to me in the stamped addressed envelope provided. After a week I will send you some final questionnaires which I hope you will once more complete and return to me.

Thank you again for your interest.

Yours sincerely,

Alison Llewellyn BA, BSc, MSc
Tel: 01225 383407 (answerphone)
Email: a.m.llewellyn@bath.ac.uk

Participant F4:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“Heavy cold and cough – difficult to shake off. Weather cold again.”

Q4: How much has thinking about your quality of life changed your plans or expectations for the future?

A = 2 (a little) “Reinforced the need to remain involved and active in creative pursuits.”

Q6: How much has thinking about your quality of life changed your mental health?

A = 2 (a little) “Made me aware of how much my vulnerability and well being is in my own hands and quite fragile.”

Q7: Helpfulness of the experience

A = long term = somewhat helpful (possibly)

Participant F2:

Q3: How much has participating in this study changed the way you think about your quality of life?

No quantitative response but comment: “It has made me realise how fortunate I am to have a positive view of my life in spite of my age and recent loss of husband.”

Q6: How much has thinking about your quality of life changed your mental health?

No quantitative response but comment: “Same answer as in 3.”

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

“Had I completed this study 18 months ago many of my answers would have been less positive because of my husband’s dementia, stay in nursing home and the consequent problems. I did have counselling a year ago and I am fortunate in the support of family and friends as well as my own ‘strength of character’!”

Participant F5:

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

“I’m sorry that I might be giving disappointing answers, but I’m too busy and involved with other things, so your questionnaire has not really made an impact on me.”

Participant F10:

No changes or comments. Neither helpful nor unhelpful.

Participant F13:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“Physically my arthritis seems to have kicked in, making my mobility slower / stiffer and brings old age much closer and the limitations with it.”

Q2: How much has your quality of life changed as a result of taking part in this study?

A = 3 (a little worse) “Because I can drive I can attend my social activities and realise how much I rely on having a little car.”

Q3: How much has participating in this study changed the way you think about your quality of life?

A = 2 (changed a little) “Just thoughts on my limitations for the future.”

Q7: Helpfulness of the experience

A = short term, medium term = somewhat unhelpful

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

“Because I am mentally alert and it is my skeleton that is causing old age problems I do not see how my answers to this questionnaire can be of any use to you. I would be interested to know your conclusions.”

Participant E2

Q3: How much has participating in this study changed the way you think about your quality of life?

A = 2 (changed a little) “Made me think about how I stand re life.”

Q7: Helpfulness of the experience

A = short term, medium term, long term = somewhat helpful

Participant F8:

No changes or comments. Neither helpful nor unhelpful.

Participant B1:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“I’m more stressed than the last time I completed the questionnaire. I feel very tense.”

Q3: How much has participating in this study changed the way you think about your quality of life?

A = 2 (changed a little) “If you asked about it, it can depend on what you focus on (i.e. which aspect). Before, I only thought about overall quality of life and it’s generally ok.”

Q6: How much has thinking about your quality of life changed your mental health?

A = 2 (a little) “I’m trying to focus on the positive side of my life so I can feel content.”

Q7: Helpfulness of the experience

A = short term = somewhat helpful; medium term = mostly helpful; long term = very helpful

Participant B2:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“I met a deadline at uni and so feel less anxious about getting work done on time and to a sufficient standard.”

Q2: How much has your quality of life changed as a result of taking part in this study?

A = 5 (a little better) “The study has made me reflect a little more about my life and all the things that I am able and willing to do. It’s good to have a wake up call every now and then.”

Q3: How much has participating in this study changed the way you think about your quality of life?

A = 3 (changed a fair amount) “Quality of life doesn’t just mean physical health and I believe now that environment is very important and I’ve come to realise that I’m very happy in my living space and that this contributes to my sense of wellbeing.”

Q4: How much has thinking about your quality of life changed your plans or expectations for the future?

A = 3 (a fair amount) “Just thinking about the question which asks about where you are in relation to your ideal helps shape my goals and helps me recognise what my goals and ideas are and what I have already achieved.”

Q6: How much has thinking about your quality of life changed your mental health?

A = 3 (a fair amount) “The process of writing/scoring scales on how I feel has helped me reflect and realise that actually I’m happier than I thought. Also it is reassuring that items such as anxiety, irritability etc. are included on scales as it suggests that I am not alone in feeling that way from time to time.”

Q7: Helpfulness of the experience

A = short term = very helpful; medium term, long term = mostly helpful

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

“Although I feel better and I do believe that was because of the study, I did struggle a little to recall what the intervention was. Thanks for helping me reflect!”

Participant C3:

No changes or comments. Neither helpful nor unhelpful.

Participant A1:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“Away day with work to Edinburgh.”

Q4: How much has thinking about your quality of life changed your plans or expectations for the future?

A = 3 (changed a fair amount) “The more you evaluate your QoL the more you realise what elements of your life make a difference to you, and the more you can focus on them.”

Q6: How much has thinking about your quality of life changed your mental health?

A = 3 (a fair amount) “Psychologically the more you can control your QoL the better state of mind you can sustain.”

Q7: Helpfulness of the experience

A = short term, medium term, long term = somewhat helpful

Participant D1:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“Job interview”

Q3: How much has participating in this study changed the way you think about your quality of life?

A = 2 (a little) “To take time to think about how I’m feeling and why.”

Q5: How much has thinking about your quality of life changed your physical health?

A = 2 (a little) “Encouraged me to do more exercise.”

Q6: How much has thinking about your quality of life changed your mental health?

A = 2 (a little) “Being more aware of how I’m feeling”.

Q7: Helpfulness of the experience

A = short term, medium term, long term = somewhat helpful

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

“I have had depression in the past and I am still taking Sertraline tablets daily.

Participant C3:

No changes or comments. Neither helpful nor unhelpful.

Participant A3:

Q7: Helpfulness of the experience

A = short term = somewhat helpful

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

I found the questionnaire very interesting to complete. It made me think that I can be quite hard on myself and on what I have achieved. But I am not sure how much of an effect it will actually have on my life. I feel it was too short an experience to have a long term effect.

Participant F15:

Q1: In the week between completing the first and second set of questionnaires, did anything change for you that might have affected your answers?

“My husband seemed a little better. My daughter seemed not at all depressed.”

Q2: How much has your quality of life changed as a result of taking part in this study?

A = 4 (about the same) “I have always felt I am very fortunate in being able to make the best of my life, but my husband has always been a bit morose and my daughter suffers from depression. I don’t think my quality of life changes except from family problems. I feel in control.

Q4: How much has thinking about your quality of life changed your plans or expectations for the future?

A = 1 (not at all) “If my husband became an invalid, I would not have any aptitude as a carer. I surprise my family by coping but I don’t have any options.

Q5: How much has thinking about your quality of life changed your physical health?

A = 1 (not at all) “I have had backache since my forties, but I’m careful.

Q8: Is there anything else you would like to tell me that has not already been covered in this questionnaire?

What about a question about memory problems. I use lists or put something in a prominent place (e.g. bank paying-in book).

Participant F14:

No changes or comments. Neither helpful nor unhelpful.

Appendix Q Study 3 participant information sheet



WHO Field Centre
for the study of quality of life



QUALITY OF LIFE INFORMATION AND WELLBEING STUDY - PARTICIPANT INFORMATION

Welcome to the University of Bath Quality of Life Survey

We are carrying out this study as part of ongoing research at the World Health Organisation's Field Centre for the Study of Quality of Life at the University of Bath. Before you decide whether to take part, you need to understand more about the study. Please read the following information carefully.

What is the purpose of the study and do I have to take part?

This study seeks to explore how understanding our own quality of life might affect the way we think about our wellbeing. It is up to you to decide whether to take part. Even if you decide go ahead you can withdraw later from the study at any time and without having to give a reason.

What will happen to me if I decide to take part?

You will be asked to complete a number of questionnaires asking about your quality of life, your feelings and your goals. A few days after you have submitted your responses, you will be sent some graphs showing your responses to the quality of life questions. You will be randomly allocated to one of two groups:

- If you are in group 1, you will be sent some instructions with your graphs for how to read them.
- If you are in group 2, you will be contacted by telephone to discuss your graphs with a researcher.

Whichever group you are in, you will also be sent a final set of questionnaires for you to complete after you have looked at the graphs. If you give your permission, we may also telephone you after a couple of months with a small number of final questions.

What are the possible benefits to me of taking part?

We cannot promise the study will help you individually but you may find at the end that you will know more about how you think about quality of life. If you feel in any way uncomfortable with any part of the study, you are free not to answer or to withdraw from the study at any time, without having to give any reason. If you experience any emotional distress as a result of the project, it may be useful to speak to your GP or to a counsellor.

Will my taking part in the study be kept confidential?

Yes. We will follow strict ethical and legal practice. All information about you will be handled in complete confidence and kept securely. Your data will be given a unique number so that you will not be able to be identified. It will only be used by researchers at the World Health Organisation Quality of Life Centre at the University of Bath and will not be passed on to anyone else. If you decide to withdraw from the study we may ask for your permission for us to use any data you have already given us. The information you give will not affect any care or services you currently receive. However, if we identify from the information you give us during the study that you are particularly vulnerable, we may ask you for your permission to notify your GP or to refer you to a relevant service.

What will happen to the results of the research study?

The broad scientific results of the study will be written up to form part of a doctoral thesis. The study may also be presented at academic conferences and published in a suitable academic journal. However, you will not be personally identified in any presentation or published document.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee. Research Ethics Committees (RECs) safeguard the rights, safety, dignity and well-being of people participating in research in the National Health Service. They review applications for research and give an opinion about the proposed participant involvement and whether the research is ethical. This study has been reviewed and given favourable opinion by South West 5 (or Frenchay) Research Ethics Committee. This study will be supervised by Professor Suzanne Skevington at the University of Bath and has also been approved by an independent University of Bath Research Ethics Committee.

If you have any questions at any time you are very welcome to contact the researcher, Alison Llewellyn on 01225 383407 or by email at a.m.llewellyn@bath.ac.uk

Thank you for your help.

Participant Information Sheet v2 29.12.10

The participant consent form is overleaf →

Appendix R Study 3 Covering letters accompanying feedback

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Department of Psychology
Bath BA2 7AY · United Kingdom
Telephone 01225 383407
Facsimile 01225 386752

Dear

Quality of life study

Thank you for completing and returning Questionnaire Pack One of our study. In the next part of the process you are asked to view some graphs and, as soon as possible afterwards, complete part two of the study.

There are a number of documents enclosed with this letter. The first is a facet chart which explains how different aspects of quality of life fit together in the World Health Organisation model. The second document entitled "How to read the feedback graphs" will give you instructions for viewing your personal graphs. The graphs enclosed show how you answered some of the quality of life questions. Please note that these graphs show only the information that you gave regarding your own quality of life. They do not show anyone else's answers and there are no right or wrong answers.

Please read the "How to read the feedback graphs" document and facet chart first. Please could you then look at the graphs by following the instructions in the "How to read the feedback graphs" document as closely as possible. You are welcome to keep graphs themselves along with the facet chart and instructions.

You will also find Questionnaire Pack Two enclosed with this letter. When you have looked at your graphs according to the instructions, I should be grateful if you would complete Questionnaire Pack Two as soon as you can. However, please do not complete this until AFTER you have looked at your graphs and please do not refer back to your graphs when you are filling in your responses.

You will also find enclosed a freepost envelope for you to use to return Questionnaire Pack Two to me in the post.

Please do not hesitate to let me know if you have any questions or need any help.

Many thanks for taking part in this study and I hope that you find your graphs interesting.

Kind regards

Alison

Enc. World Health Organisation Quality of Life Assessment Facet Chart
How to read the feedback graphs
3 x graph pages – participant number
Quality of Life Information & Wellbeing Study Questionnaire Pack Two
Freepost envelope



Department of Psychology
Bath BA2 7AY · United Kingdom
Telephone 01225 383407
Facsimile 01225 386752

Dear

Quality of life study

Thank you for completing and returning part one of my study and for agreeing to talk to me on:

[insert date & time]

As promised, please find enclosed your Quality of Life graphs. Please could arrange to have them in front of you to look at as we talk?

The graphs show you how you answered some of the quality of life questions. Please note that they show only the information that you gave regarding your own quality of life. They do not show anyone else's answers and there are no right or wrong answers. Also enclosed is a facet chart which explains how different aspects of quality of life fit together in the World Health Organisation model. You are welcome to keep graphs and the facet chart for your own information.

You will also find Questionnaire Pack Two enclosed with this letter. Please do not complete this until AFTER we have spoken on the phone and please do not look back at your graphs when you are filling in your responses.

Please do not hesitate to let me know if you have any questions or if you need to rearrange the time of our conversation. Otherwise I will telephone you as agreed.


I look forward to talking to you soon.

Kind regards

Alison

Enc. World Health Organisation Quality of Life Assessment Facet Chart
3 x graph pages – participant number
Quality of Life Information & Wellbeing Study Questionnaire Pack Two
Freepost envelope

Appendix S Study 3 Alternative verbal feedback protocol



WHO Field Centre

for the study of quality of life

Participant id

Quality of Life Study 3 – Telephone feedback – notes

Date

Time

Is it convenient to talk now?

Have you printed the graphs and the facet sheet or can you view them as we talk?

Do you have them in front of you now?

Introduction

○ The graphs give you your personal feedback showing how you responded to each question in the WHOQOL-BREF questionnaire.

○ There were questions about many aspects of quality of life. So if you look at the facet sheet, this shows you how all these aspects fit together. For example, questions about pain, sleep and mobility all fit into you physical health; questions about your feelings and your self esteem fit into your psychological health and so on.

○ Please note that these graphs show only the information that you gave regarding your own quality of life. They don't show anyone else's answers. Neither are there any right or wrong answers, it's just your life as you saw it to be when you answered the questions.

Domain scores

○ Firstly please look at the graph at the top of page 1, called "Domain Scores". The bars show you how you saw the broad aspects of your quality of life to be, for example, overall physical health. The triangles show you how important you saw these aspects to be to you.

○ The scores on this graph range from 0-100 where a blue bar of 50 means you saw your QoL when you completed the questionnaire as moderately good and a triangle at 50 means you saw that aspect to be moderately important. The higher the score the better you saw your QoL or the more important that area was.

○ So looking at this first graph it suggests you felt your QoL was less than good in terms of [but that it was better for]

At the same time you felt that were at least moderately important to you. What we'll do is go on to look at this in more detail by looking at your responses to individual questions.

Facet scores

○ So if we look at the graph on p1 called overall QoL and Health. This relates to your answers to the first two questions you were asked. You were asked to circle responses from 1 – 5 where for each aspect 1 was very poor QoL, or not important, and 5 was very good QoL or extremely important.

○ The first question you were asked was "How would you rate your QoL" to which you responded "....." and the second question was "How satisfied are you with your health" to which you said ".....".

Now I'd like you to look at the responses you gave for individual questions relating to how you saw your quality of life. Please could you turn to page 2?

For each domain in turn:

Looking at the top graph on p2 which shows your responses to questions about physical health, your responses suggest you were dissatisfied with your physical health in terms of [and I noticed also from you questionnaire that you have to put up with a number of difficult health conditions at the moment, which can't be easy for you].

Repeat for each domain.

Now I'd like to look at the more positive aspects of the graphs. (Find any 3s, 4s or 5s)

This graph is about (if 3) You can see here that in relation to [facet(s)] you suggested that you were neither satisfied nor dissatisfied indicating that you saw you QoL life as better here than some of the previous aspects we have looked at in [domain] for example.

And then if we look at [domain] about (describe domain) there are also some more positive messages. For example, you said you felt that for (list eg moderately safe in your daily life, that you feel reasonably satisfied with the availability of information you need in your day-to-day life, and that you are neither satisfied nor dissatisfied with your access to health care services and with your transport arrangements.)

(Find most positive facet(s)) The aspect(s) of your QoL with which you feel most satisfied is [facet(s)] with which you said you were so that's an area where you feel your QoL is very good / quite good / at least moderately good.

Gaps >= 2:

It is noticeable that for many aspects of your QoL there are gaps between how you saw your QoL to be and how important this aspect was for you. For example, you saw aspects of [domain] to be important to you, but you also felt your quality of life was poor in these areas. The same is true for

Where there are gaps like these between QoL and importance, it might be that you want to think about what you might be able to do to make these gaps smaller. Of course I appreciate that many aspects may be outside of your control and this is possibly particularly true of your physical health. Where this is true it may be that you simply can't do anything yourself to improve your QoL as you see it because you cannot change your circumstances. However, one other way to make the gaps smaller is to try to make these aspects less important to you in some way by rethinking how you feel about them.

Gaps <2:

There are also areas in your graphs where we can see where the gaps are much smaller and this is especially the case in relation to [domain]. For example you can see that the gaps are very small for [facets]. For these areas there isn't a gap between where you saw yourself and the importance rating, or perhaps, where you would prefer to be. So the suggestion is that how you saw your QoL also matched with your expectations for that area.

May I ask a few final questions?

Do the graphs make sense for you?

Is there anything on the graphs that particularly surprises you?

Do you think you have learned anything from looking at the graphs?

[If required:

Do you think that, having looked at the graphs, it might be useful to talk to your GP or about those aspects about which you are less than satisfied or to talk to someone else who might be able to help?

Would you allow me to contact your GP to tell him it might be useful for you to see him?]

Appendix T Study 3 Demographic questionnaire

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About you

Please answer the following questions to tell us more about you. As with all your answers, the information you give us here will be kept strictly confidential.

1. How old are you?

☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75+

2. What is the highest level of education you received? *Please tick one*

☐ Primary School
☐ Secondary School
☐ Technical or further education college
☐ College / University
☐ Post-graduate

3. How would you describe your ethnic origin? *Please tick one*

☐ White
☐ Black Caribbean
☐ Black African
☐ Black (other)
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Chinese
☐ Other Asian
☐ Other ethnic background (not Asian)

4. What is your **current** marital status? *Please tick one*

☐ Single (never married)
☐ Married
☐ Partnered (not married)
☐ Single / Separated / Divorced
☐ Widowed

Please turn over →

5. What are your **current** living arrangements? *Please tick one*

☐ Living alone
☐ Living with partner/spouse/family
☐ Living in residential care/nursing home
☐ Living in sheltered housing
☐ Other (please specify)

6. Where is your home located? *Please tick one*

☐ Centre of a town or city
☐ Suburbs of a town or city
☐ In the countryside

7. Do you live in the UK? *Please tick one*

☐ Yes
☐ No

8. What **is**, or **was**, your main occupation? *Please tick one*

☐ Professional or higher administrator e.g. doctor, teacher, engineer, accountant, business executive
☐ Sales and service e.g. sales manager, shop assistant, police officer, hairdresser
☐ Skilled and clerical e.g. motor mechanic, electrician, secretary, bookkeeper, office manager
☐ Semi-skilled or unskilled e.g. bricklayer, bus driver, labourer, porter)
☐ Farming e.g. farmer, farm labourer
☐ Military
☐ Household duties or carer
☐ Voluntary work
☐ Other (please specify)

9. Please tick the **one** of the following statements that **mainly** applies to you **currently**:

☐ Employed full time
☐ Employed part time
☐ Only occasionally employed
☐ Self-employed
☐ Unemployed, looking for work
☐ Retired
☐ Unemployed, unable to work at the moment
☐ Unemployed, permanently unable to work
☐ Student
☐ Household duties or carer
☐ Voluntary work
☐ Other (please specify)

Appendix U Study 3 EQ-5D 5-level version, source: The EuroQol Group (2010)

EQ-5D

Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY

I have no problems in walking about

I have slight problems in walking about

I have moderate problems in walking about

I have severe problems in walking about

I am unable to walk about

SELF-CARE

I have no problems washing or dressing myself

I have slight problems washing or dressing myself

I have moderate problems washing or dressing myself

I have severe problems washing or dressing myself

I am unable to wash or dress myself

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities

I have slight problems doing my usual activities

I have moderate problems doing my usual activities

I have severe problems doing my usual activities

I am unable to do my usual activities

PAIN / DISCOMFORT

I have no pain or discomfort

I have slight pain or discomfort

I have moderate pain or discomfort

I have severe pain or discomfort

I have extreme pain or discomfort

ANXIETY / DEPRESSION

I am not anxious or depressed

I am slightly anxious or depressed

I am moderately anxious or depressed

I am severely anxious or depressed

I am extremely anxious or depressed

Please turn over →

UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group

We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

100 means the best health you can imagine.

0 means the worst health you can imagine.

Mark an X on the scale to indicate how your health is TODAY.

Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =

The best health you can imagine

100

95

90

85

80

75

70

65

60

55

50

45

40

35

30

25

20

15

10

5

0

The worst health you can imagine

UK (English) v.2 © 2009 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group

Appendix V Study 3 Post-study evaluation of change questionnaire

Study Evaluation

We are interested in changes that may have happened for you whilst taking part in our study. Please complete the following changes as fully as you can.

Please read each question and **circle** the number on the scale for each question that gives the best answer for you.

1. How much has your quality of life changed **as a result** of taking part in this study?

	Much worse	Worse	A little worse	About the same	A little better	Better	Much better
<i>My quality of life is now...</i>	1	2	3	4	5	6	7

1(a) If your quality of life **has** changed at all, in what ways has it done so?
.....
.....

2. In the period between completing the first and second set of questionnaires, did anything else change for you that might have affected your answers the second time? *Please tick one*

☐ Yes
☐ No

2(a) If yes, what changed?
.....
.....

3. How much has taking part in this study changed the **way you think** about your quality of life?

	Not at all	A little	A moderate amount	A lot	Completely
<i>The way I think about my quality of life has changed...</i>	1	2	3	4	5

3(a) If the way you think about your quality of life **has** changed, in what ways has it done so?
.....
.....

4. How much has taking part in this study changed **your plans or expectation for the future**?

	Not at all	A little	A moderate amount	A lot	Completely
<i>My plans or expectations for the future have changed...</i>	1	2	3	4	5

4(a) If your plans or expectations **have** changed, in what ways have they done so?
.....
.....

Please turn over →

5. How much has taking part in this study changed **your physical health**?

	Not at all	A little	A moderate amount	A lot	Completely
<i>My physical health has changed...</i>	1	2	3	4	5

5(a) If your physical health **has** changed, in what ways has it done so?
.....
.....

6. How much has taking part in this study changed **your psychological health**?

	Not at all	A little	A moderate amount	A lot	Completely
<i>My psychological health has changed...</i>	1	2	3	4	5

5(a) If your psychological health **has** changed, in what ways has it done so?
.....
.....

7. How much has taking part in this study changed **your social relationships**?

	Not at all	A little	A moderate amount	A lot	Completely
<i>My social relationships have changed...</i>	1	2	3	4	5

5(a) If your social relationships **have** changed, in what ways have they done so?
.....
.....

8. How much has taking part in this study changed **your environment**?

	Not at all	A little	A moderate amount	A lot	Completely
<i>My environment has changed...</i>	1	2	3	4	5

5(a) If your environment **has** changed, in what ways has it done so?
.....
.....

Appendix Vii Study 3 Post-study evaluation of change questionnaire

9. How helpful will your experience of this study be to you in the future?

	Very unhelpful	Mostly unhelpful	Somewhat unhelpful	Neither helpful nor unhelpful	Somewhat helpful	Mostly helpful	Very helpful
a. In the next two weeks?	1	2	3	4	5	6	7
b. In the next three months?	1	2	3	4	5	6	7
c. Longer than three months?	1	2	3	4	5	6	7

10. Is there anything else you would like to tell us that has not already been covered in these evaluation questions?

.....

.....

.....

.....

11. How did you find out about this study? *Please tick one*

☐ Letter from G.P.

☐ On a website

☐ Poster / leaflet

☐ Someone told me about it

☐ Other (please specify)

12. Please tell us briefly why you were interested in taking part.

.....

.....

Please turn over →

You have now completed our study.

Many researchers have looked at how different groups of people rate their quality of life. This information has often been used to get a picture of the wellbeing of large groups of people and to help improve health care. However, not many studies have considered how the process of thinking about quality of life might affect individuals' wellbeing.

The study you have just completed is about whether giving people feedback on their quality of life affects their later thoughts about their wellbeing.

It is hoped that by understanding more about how feedback on quality of life can affect wellbeing, we can develop a way of helping people meet the challenges they face in life. We are particularly interested in how this might be used for people with a chronic illness.

If you have experienced any emotional distress as a result of the project, it may be useful to speak to your GP or to a counsellor.

This study is part of the ongoing research taking place at the World Health Organisation's Field Centre for the Study of Quality of Life at the University of Bath. We may contact you again in a few months time to reflect on your experience. Again it is up to you to choose whether to take part. If you want to know more about this, or other studies we are conducting, please contact:

Alison Llewellyn
PhD Researcher
Department of Psychology
University of Bath

Tel: 01225 383407
Email: a.m.llewellyn@bath.ac.uk

Please tick this box if you would like to be sent a summary of results at the end of this study. ☐

Please tick this box if you are happy for us to contact you again if we have further questions related to this study. ☐

Thank you again for your help with this study, it is much appreciated.

Appendix W Study 3 SPSS syntax created to transform WHOQOL Importance scores

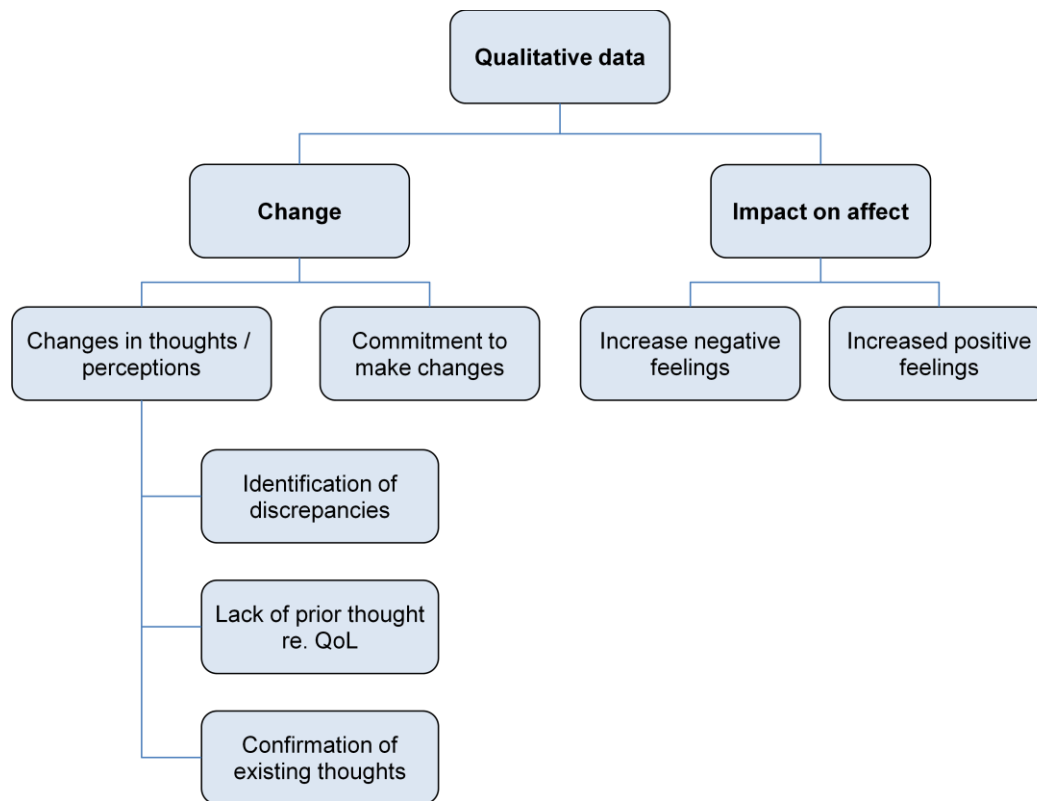
```
RECODE iq1QoL iq2Health iq3Pain iq4Energy iq5Sleep iq6PositiveFeelings  
iq7Cognitions iq8SelfEsteem iq9BodyImage  
iq10NegFeelings iq11Mobility iq12Activities iq13Medication iq14Work  
iq15Relationships iq16Support iq17Sex  
iq18Safety iq19HomeEnvt iq20Finances iq21HealthCare iq22Info iq23Recreation  
iq24PhysicalEnvt iq25Transport  
iq26Spirituality  
(1=1) (2=2) (3=3) (4=4) (5=5) (ELSE =SYSMIS).
```

```
COMPUTE IqPHYS=MEAN.6(  
iq3Pain,iq13Medication,iq4Energy,iq5Sleep,iqMobility,iq12Activities,iq14Work)*4.  
COMPUTE IqPSYCH=MEAN.5(  
iq6PositiveFeelings,iq26Spirituality,iq7Cognitions,iq9BodyImage,iq8SelfEsteem,iq1  
0NegFeelings)*4.  
COMPUTE IqSOCIAL= MEAN.2( iq15Relationships,iq17Sex,iq16Support)*4.  
COMPUTE IqENVIR=MEAN.6(  
iq18Safety,iq24PhysicalEnvt,iq20Finances,iq22Info,iq23Recreation,iq19HomeEnvt,i  
q21HealthCare,iq25Transport)*4.
```

```
COMPUTE IqTPHYS=(IqPHYS-4)*(100/16).  
COMPUTE IqTPSYCH=(IqPSYCH-4)*(100/16).  
COMPUTE IqTSOCIAL=(IqSOCIAL-4)*(100/16).  
COMPUTE IqTENVIR=(IqENVIR-4)*(100/16).
```

```
EXECUTE.
```

Appendix X Study 3 Qualitative analysis coding framework



Appendix Y Study 3 Coded qualitative transcripts

1. Change

1.1 Changes in thoughts /perceptions

Plans & expectations	Not to take quality of life for granted	P41
Psychological	Made me stop & think	P41
Participation	It helps you think about your life in general.	P42
Psychological	Made me think	P46
QoL thinking	I realize that age does make a difference to ones quality of life because the body is less able to cope	P47
Participation	... it was a beneficial exercise to do for self-evaluation.	P49
QoL thinking	To make me think of what area I can improve myself on	P59
Plans & expectations	Given me time to think of my 'lot'...	P61
Psychological	New awareness of looking at myself – carrying out self-appraisal.	P61
Social	Disappointed in myself for negative thoughts – made aware	P61
QoL thinking	I don't normally think about my quality of life. Perhaps I will now.	P63
QoL thinking	Thinking a little more realistically about personal relationships	P66
Social	More thought regarding relationships with spouse.	P66
Plans & expectations	I am now focusing on a smaller number of issues.	5168032
QoL change	Able to identify the main issues affecting my quality of life.	5168032
QoL change	Have a better understanding of what I need to obtain a better quality of life.	5205426
Plans & expectations	Have a clearer understanding.	5223929
Plans & expectations	Made me think about the way I use my limited energy	5263007
Psychological	A bit more thoughtful	5313423
QoL change	I now consider things in more depth	5313423
QoL thinking	Slightly more critical; reconsidering how I might best act to minimise the effect of the illness upon my quality of life.	5317213
QoL thinking	I have reassessed how important these things are to me.	5332700
QoL change	Has made me more aware of issues of which I was not conscious...	5336689
Participation	To make me think about me and my lifestyle and to appreciate what I have...	5352396
Plans & expectations	I probably will think about one or two aspects of my life slightly differently.	5360374
QoL change	I have a different view of what is important to me	5360374
QoL thinking	I have a slightly different way about thinking about what is important	5360374
Plans & expectations	I will pay more attention to other parts which I have never thought of it as part of quality of life	5405962
QoL thinking	I now have a clearer idea of which parts of my quality of life I am satisfied in and which I am less so.	5412297
QoL thinking	Seeing the areas in black and white and how important they are to me personally has made me look at those aspects of my own quality of life in a different way.	5413920
Plans & expectations	May have made me reconsider the value of my relationship.	5417365
QoL change	... this will probably help me identify less strong areas	5417365
QoL thinking	I'll now think more carefully about why things are important to me and whether it's 'worth' worrying about them if	5429275

1

	actually they are pretty good anyway or not that important in the overall scheme of things.	
QoL thinking	Putting problems in perspective and realise not as bad as can be perceived initially.	5435981
Psychological	I understand that my body image has an impact on my outlook...	5729941
Psychological	Am more conscious of this domain	5732790
QoL thinking	It has made me think about my social relations and psychological health a lot more.	5748311
Plans & expectations	To think about quality of life when making certain decisions and remember those things I think are important to me and reflect on how I rate my quality of life.	5750068
QoL change	It has raised my awareness of thinking about how important certain aspects are to me.	5750068
Psychological	I drew my attention to some aspects of my health that are important but I had failed to recognize their importance until now	5752513
Psychological	I am reflecting more on Quality of Life	5807945
QoL thinking	I have thought more about what is important to me	5807945
QoL change	Realised that I think too much about finances and my work is way too important to me over other things that should mean more to me such as recreation.	5838858
QoL thinking	...look into what means more to me not just work	5838858
QoL thinking	It has highlighted two areas to me that I wasn't really aware of previously...	5840560
QoL thinking	... it has made me think about all the different aspects that can affect your life and how they are connected.	5821854
Psychological	Made me more aware of myself	5847781
Social	Am thinking about relationships with friends etc	6087527
Social	Made me think about them more.	6115171
Physical	It has let me examine my overall health...	6141724
QoL change	It has made me question and reflect upon certain areas of my life...	6141724

1.1.1 Identification of discrepancies

QoL change	Was surprised to find out there was such a large gap between what was important and the quality of life- particularly with regards to psychological health.	5205426
Psychological	Recognising the gap between actual and where I want it to be	5323833
Anything else?	The two areas where there are gaps between what I wanted and what I have I am doing something to change	5337081
QoL change	[I can now think about the] gap between aspiration and reality, rather than absolutes	5493126
QoL change	It has caused me to reflect on the relationship between actuality and expectations, as well as consider the now, recent past and future in a more structured way.	5548364
QoL change	Now I know... which elements of "Quality of Life" I should change/improve to meet my expectations.	5563254
Anything else?	It has been very interesting, both seeing the gaps and confirming where I'm doing well.	5571043
Plans & expectations	I have been thinking about how to bridge the gaps between my reality and my expectation!	5807945
Plans & expectations	[I realised] that energy and lack of recreation time were not meeting my ideal expectation	5840560

2

1.1.2 Lack of prior thought re QoL

QoL thinking	I had never really thought about my quality of life before the survey...	P41
QoL thinking	I don't normally think about my quality of life. Perhaps I will now.	P63
QoL thinking	Did not think about [QoL] before, but find myself thinking now	P86
Plans & expectations	I will pay more attention to other parts which I have never thought of it as part of quality of life	5405962
QoL thinking	I don't think I had really thought about my quality of life previously...	5750068
QoL thinking	In many ways I didn't really think about [QoL] that much before	5921854

1.1.3 Confirmation of existing thoughts

QoL thinking	A helpful and thought-provoking analysis, but mainly reassuring...	P16
Psychological	Has underlined some areas that I was aware of...	P49
QoL thinking	It's good to see where I am scoring well, as well as the areas where I already knew I was scoring badly.	5227803
QoL thinking	It showed me that what I think about my life is consistent with how I express it	5280496
Anything else?	It confirmed what I already knew.	5337081
QoL thinking	Reconfirmed the importance of certain aspects of my life...	5382226
Anything else?	Has confirmed a lot of what I thought about myself in various aspects	5406272
Psychological	nice to know I am not barking up the wrong tree	5409687
QoL thinking	re iterated what I have been thinking and feeling	5409687
QoL thinking	It is interesting, and lucky for me, to see that the areas of my life are roughly in line with the importance I give them	5494154
Anything else?	It has been very interesting... confirming where I'm doing well.	5571043

3

1.2 Commitment to make changes

QoL thinking	The chart has highlighted issues that I need to address	P46
Plans & expectations	I have to live at a slower pace and accept it as a natural way of life.	P47
Psychological	Has underlined some areas that I was aware of but can now concentrate on doing something about them.	P49
QoL change	Study has made me more aware of different aspects of quality of life & inspired some changes to improve same.	P49
Environment	Trying to improve my allotment	P54
QoL thinking	To make me think of what area I can improve myself on	P59
Physical	Try to find more ways of taking exercise	P62
Psychological	I now feel positive about being able to put in place mechanisms to tackle certain aspects of psychological health related to negative thinking...	5168032
QoL change	[I have been able to] ...focus on the 2 [facets] that will have the biggest impact, so improving overall quality of life in giving me a positive attitude and confidence to tackle issues.	5168032
QoL thinking	[I will be able] ...to tackle the most important issues first that will directly improve my quality of life (sleep, energy) and have a positive impact on other quality of life areas, particularly psychological health.	5168032
Plans & expectations	I will be taking more time to look at where the problems lie in my life and how I can go about changing them to make me feel better.	5205426
QoL thinking	I realise that there are many things I could do to improve my quality of life, and that these are primarily related to emotional/psychological health.	5205426
Psychological	Recognising the gap between actual and where I want it to be and how I will address this	5323833
Plans & expectations	I will try to be more aware of the positives and take action, where possible, to address the negatives.	5336989
Social	I will try to be more aware of the support received.	5336989
Anything else?	The two areas where there are gaps between what I wanted and what I have I am doing something to change things already.	5337081
Participation	To make me think about... what I have and want to keep or need and what I have that I don't want to keep or need and can change or discard and the resources I need to retain and/or make changes.	5352396
QoL thinking	... given me the impetus to "work at" those areas that are important to me.	5382226
Psychological	I should be more positive on my outlook on life.	5382635
Plans & expectations	emphasised the need to address the poorer outcomes	5409687
QoL thinking	By quantifying these [QoL] areas I can make plans to improve my quality of life.	5412297
Plans & expectations	I now see the areas I need to work on to reach my arrows!	5413920
Psychological	... some areas of my life are good, whilst others are specific and isolated and can be worked on.	5417365
QoL change	...this will probably help me identify less strong areas and see where small and easy changes can be made to have a relatively significant impact...	5417365
QoL thinking	... helps me to identify and isolate areas in need of improvement. This is great because rather than having the insurmountable task of 'trying to make my life better', I can work on specific areas with specific actions.	5417365
QoL thinking	Made me realise how lucky I am and therefore try very hard to preserve it.	5419095
Social	I want to work towards the social environment and social relationships that I want to be at.	5419095

4

QoL thinking	Now I know what I should work on more, I mean which elements of "Quality of Life" I should change/improve to meet my expectations.	5563254
Environment	I'm trying to change my environment, but it is a lengthy process	5571043
QoL thinking	It has been useful to see it visually and think about how to make a few more positive changes	5571043
QoL thinking	It's a reminder to maintain your quality of life as well as you can.	5677587
Plans & expectations	can begin to think about appropriate action to take	5732790
Psychological	Am more conscious of [the psychological] domain and to try to be positive and not worried...	5732790
QoL thinking	helped me to crystallise which domains to work on	5732790
Social	It has made me realise that my social relationships are not adequate and need changing	5748311
QoL change	It has [enabled me] ... keep a focus on improving [important aspects] rather than spending time on things not so important.	5760068
Plans & expectations	I may need to work on self-esteem around body image.	5766711
QoL thinking	To be more aware of what is important to you and to take steps to change it if you can.	5785182
Plans & expectations	I need to continue to tell myself all the good things that I am able to do/feel/be	5834486
QoL thinking	...perhaps now I can work on ways to improve those areas [that I wasn't really aware of previously]	5840580
Psychological	[I should] perhaps focus on working towards improved feelings about myself in terms of negative thoughts.	5862289
Psychological	Perhaps focus on working towards improved feelings about myself in terms of negative thoughts.	5862289
Environment	I have realised that my work environment is not as good for me as before therefore I need to take steps to change it and move on.	5821854
Physical	It has let me examine... how I could improve my physical health through my psychological health.	6141724
QoL change	It has made me question and reflect upon certain areas of my life and how I could take action to help improve these areas.	6141724

5

2 Impact on affect

2.1 Increased negative feelings

Psychological	I have realised I do get depressed	P53
QoL change	More concerned about health & finances	P54
QoL thinking	...made me think, slightly depressive	5263007
QoL thinking	... I've come to believe that the things which bring my quality of life down are largely beyond my control which is frustrating, scary and can lead me to feel angry and bitter (so I try not to think about it).	5283674
Psychological	Possibly feel a bit worse from seeing the gaps on the charts	5396114
Participation	feel frustrated with certain situations (as a result of taking part in the study)	5435981

2.2 Increased positive feelings

Psychological	Feeling a little more positive	P60
QoL change	Not feeling so anxious	P60
Physical	[Taking part in the study has made me feel] grateful – and awareness of the skill of "positive thinking".	P61
QoL thinking	I am grateful for my "positive" thinking	P61
Plans & expectations	I am now focusing on a smaller number of issues and feel more able to cope with doing so.	5168032
Psychological	I now feel positive... and don't feel so overwhelmed.	5168032
QoL change	Able to identify the main issues ... giving me a positive attitude and confidence to tackle issues.	5168032
QoL thinking	It's good to see where I am scoring well...	5227803
Psychological	I've focused on the fact that my quality of life could be significantly worse which makes me feel more positive...	5283674
Psychological	I've realised I am more resilient than I thought in the face of physical problems though which is reassuring.	5283674
QoL thinking	I've focussed on the fact that my quality of life could be significantly worse which makes me feel better...	5283674
QoL change	Has made me more aware of issues... and therefore I feel empowered to address them.	5336989
QoL thinking	On paper it looked better than I expected.	5375241
Psychological	My outlook on my current lifestyle is much more positive.	5412297
Psychological	Almost gives me hope that not all is lost...	5417365
Psychological	Almost gives me hope that not all is lost and some areas of my life are good, whilst others are specific and isolated and can be worked on.	5417365
QoL thinking	It feels less like my overall life is a general disappointment...	5417365
Psychological	I feel happier	5419095
Psychological	more positive	5435981
QoL change	[As a result of the study I now] focus on good things and living more in present than worrying about things cannot do	5435981

6

	anything about	
QoL thinking	[Taking part in the study has made me think] more positively	5747238
Psychological	Generally feel more positive	5750088
Psychological	Slightly more optimism	5834486
Psychological	think less of [negative] body image - I am who I am	5838858
QoL thinking	[Taking part in the study has] made me see i am generally quite positive about life and lucky to have many aspects of quality of life.	5862289
Psychological	i feel more positive	5921854
QoL change	i think from doing this study it has made me realise how lucky i am that my quality of life is so good and that i dont really have any issues in relation to it.	5921854

Appendix Z Study 4 Semi-structured interview questions

Thank you for agreeing to answer some more questions about the Quality of Life study you took part in.

This interview should take about 20 minutes.

I would like to write down your replies, are you happy for me to do this? Yes / No

Would you also be happy for me to record our conversation on audiotape, just so that I can make sure your responses are written down correctly? Yes / No

I must also let you know that the audiotape will be destroyed at the end of the study and anything you say, or that I write down, will be made completely anonymous so that you cannot be identified.

Also, just as when you completed the surveys before, there are no right or wrong answers. Please just be as honest as you can.

Participant ID Interview Date: Time commencedfinished.....

Firstly, can you please think back to when you had the graphs in front of you?							
Q 1	Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?			<div style="display: flex; justify-content: space-between;"> → </div>			
				5 minutes or less	5-10 minutes	More than 10minutes	Other
Q 2	Have you thought about the QoL feedback with the graphs since you took part in the study?			<div style="display: flex; justify-content: space-between;"> → </div>			
	No	Yes		5 minutes or less	5-10 minutes	More than 10minutes	Other
a)	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div> <div> <p>What did you think about? (Did anything prompt this)</p> <p>(Prompt: Is there anything else?)</p> </div> </div>						
Q3	Did you look at the graphs again after you had finished taking part in the study?			<div style="display: flex; justify-content: space-between;"> → </div>			
	No	Yes		When did you look at them again? (Prompt: how long after you first saw them?)			
a)	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div> <div> <p>Was there any particular reason why you looked at the graphs again?</p> </div> </div>						
b)	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div> <div> <p>Which aspect(s) did you focus on? (Can you tell me why?)</p> </div> </div>						
c)	<div style="display: flex; align-items: center;"> <div style="border: 1px solid black; width: 100px; height: 100px; margin-right: 10px;"></div> <div> <p>What new thoughts did you have?</p> </div> </div>						

Appendix Zii Study 4 Semi-structured interview questions

Q4	Did you show the graphs to anyone?	No	Yes →	Who did you show them to?	Spouse / partner	Other family member	Friend	Doctor	Other (describe)
a)				What did you say to them?					
b)				What did they say to you? (What did you conclude?)					
Q5	Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?	No	Yes →	Who did you discuss the information with?	Spouse / partner	Other family member	Friend	Doctor	Other (describe)
a)				What did you say to them?					
b)				What did they say to you? (What did you conclude?)					

Q6	Who (else) would you want to show the graphs to, or discuss them with, if you could?	No-one	Some-one →	Who? →	Spouse / partner	Other family member	Friend	Doctor	Other (describe)
a)				Why?					
Q7	Was there anything at all that you did as a result of looking at the graphs?	No	Yes →	What did you do? (Why / why not?) (Prompt: purpose)					
Q8	What could we have provided that might have helped you to better use the information you were given?	A leaflet	An action plan to complete	Advice from a doctor or health professional	Seeing a counsellor	Other (describe) (e.g. follow up phone call)			
Q9	Do you think QoL information would be useful to share with a Health Professional?	No	Yes →	Why?					

Appendix Ziii Study 4 Semi-structured interview questions

Q10	What would you want a Health Professional to do with that information? <i>(Why?)</i>	
Q11	Do you think Health Professionals should be made more aware of how their patients see their QoL? <i>(Why?)</i>	
Q12	How do you think QoL feedback, like the graphs you were given, could make a positive difference...	
a)	... to you? <i>(Why?)</i>	
b)	... to other people? <i>(Why?)</i>	

Thank you so much for taking part. It is very much appreciated.

Appendix AA Study 4 Interview transcripts

P55 [01]

Monday 20th June, 2011

10.32 am – 10.44 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

I don't think all that long to be honest. I'm not a graph person.

(Prompt)

About 10 minutes. A little bit more than 10.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

No

Q3 Did you look at the graphs again after you had finished taking part in the study?

No

Q4 Did you show the graphs to anyone?

No

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

My wife

(Why?)

Because she lives with me, that's it and, you know, we talk about everything really. I do have children but they're grown up and doing their own thing. I suppose they don't want to listen to Dad's problems.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No

Q8 What could we have provided that might have helped you to better use the information you were given?

I can't think of anything off the top of my head.

(Prompt)

Yes probably to have discussed it a little bit more with a health person. But of course until you've actually got it there in front of you, you don't really know how deep it's going to go and how it's going to affect your thought towards it. A bit more information prior might have made me think a bit more deeper about it.

Q9 Do you think QoL information would be useful to share with a Health Professional?

Yes

(Why?)

In all of those [domains of QoL] I normally feel pretty good about myself. My only big worry about myself is that as you get older you deteriorate mind-wise - I'm certainly beginning to forget more things. Knees and joint and hips etc. But I try and keep myself fit. I try and swim every day.

I watch my weight, watch what I eat. I watch what I drink. I try and look after myself but I always have done. Being an ex military man, that's always been at the forefront. But I do see a lot of my friends now; some have passed on; they're going down with hip problems, knee joints and Alzheimers etc. That's what worries me more than anything.

Q10 What would you want a Health Professional to do with that information?

Well probably advise me in preparation for down the line, down the years. They having seen it within other patients would say well your best bet was to plan this way or do this way or this is the sort of food you should be eating or don't do those exercises, these exercise might do damage to you - I'm thinking of knees and joints again now.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes I do, especially now with more and more talking about we're going to live longer. I mean, we don't know that but we're going to supposedly live longer and it's going to cost the government, the world, a lot more to keep us going. And there's not a lot of young ones coming on. I think families are cutting down, you know, the amount of children they're having. And of course it's their children who are going to keep us in old age and keep feeding us basically.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

Yes, I think so, definitely. Again it's a guide for yourselves isn't it? This is the way he's going.

This is what's happening to him etc., what can we be doing to help. You know, what can we suggest here.

(Do you think it would be something helpful to do, perhaps on an annual basis?)

Yes, to do a monitor. Probably every 12 months or something like that. Even six months. I think the older you get the shorter you should do it.

Other comments

I mean, in talking to you, it makes you think a little more deeper. It triggers it off in your mind.

I think, you know, maybe you could do this or do that. Maybe produce a little paper to say "do you think you should be looking at this, do you think you should be thinking about this?" Because you see a broader aspect of it than we do, you are in contact with more people than I am, and obviously you have more information.

P50 [03]

Wednesday 22nd June, 2011 9.00 am – 9.12 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

About 15 minutes.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

Well, that is difficult, yes and no really. Well I was just coming off HRT and, you know, I was on happy pills as they call them. I'm [now] off HRT and still on the happy pills. My quality of life, at the present moment, when I was thinking about it, is not as good as it should be.

(Did you reflect back on the graphs?)

No, not 100% no.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No

Q4 Did you show the graphs to anyone?

Yes – my husband. Just [to tell him] what I was taking part in really.

(What did you say to him?)

How honest I had been on it and it was a good study really.

(What did he say to you?)

Well, he thought that what I had put was completely right. You know, because he knows how I was feeling. He's much much happier with me [now] and the way I am.

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No I didn't.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

Probably my best friend.

(Why?)

Because we talk a lot about our feelings and what have you, how we are.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, not really I don't think.

Q8 What could we have provided that might have helped you to better use the information you were given? (Prompt: Is there anything we could have done.....suggested you spoke to your doctor or ..)

Yes probably, because I am not a great one for going to the doctor to be honest.

Q9 Do you think QoL information would be useful to share with a Health Professional?

I would think so yes.

(What do you think the benefit of that would be?)

Well to help other people really. Or for the doctor or the health people to realise how people feel.

Q10 What would you want a Health Professional to do with that information?

I'm a bit stuck on that one.

(Prompt: I'm thinking whether it might help them to plan your treatments better..)

Well yes, but I have a very good doctor to be honest. A very good one.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I often think back to the graphs, I haven't got it out but [think back to] what the quality of life was then. Since then I've gone through different patches really.

(Have you compared how you felt then with how you feel now?)

Yes I have a bit. I've come off HRT and I'm suffering quite badly.

At this present moment I've got terrific hot sweats... which are making quality of life quite bad really.

(Do you think going back to your GP and talking about your quality of life now would be helpful for you?)

Yes I do, really, if I went back.

But like I said, I'm not a great one for going to the doctor every five minutes.

Other comments

(Would it be useful to repeat to compare back?)

Yes, it would be really because you just carry on with life don't you, and you don't really think of it until one of these sweats come over you. You carry on normally. In myself I feel

better because the anxiety's not there so much now with the tablets but I'm having to go through this now.

P92 [04]

Wednesday 22nd June, 2011 10.00 am – 10.18 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Probably ten minutes going through them because it's not easy is it to just give a definite answer.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

Not a great deal no, I have to be honest.

(Did you think about quality of life since you took part?)

Well I think we've gone through quite a trauma this last year, with my brother dying last year and then my daughter's had breast cancer and she's gone through chemotherapy and she's just having radiotherapy. So, yes it does make you think about the quality of your life.

(Did you reflect back on the feedback you were given without necessarily looking at the graphs?)

A little bit, yes.

(What did you think about in particular?)

Well I think as you get older you've got to think about your mortality and the quality of your life.

We're very fortunate that we've got reasonable pensions, both of us, and that we can help our children. So that sort of view I had of the... in a way we're more fortunate than a lot of people in that way. I feel that there are people who are a lot worse off than we are, and looking at the graph I realised that we were probably at the top end of being fortunate, that at least we were comfortably off. Both of us are reasonably fit, we play golf, but for our age, we're not doing badly. You know, when you reflect on it.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No

Q4 Did you show the graphs to anyone?

No

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

Yes. Well I talked to my husband. My husband's extremely deaf, that's one problem we have. I mean deaf as well, you know, he's gradually lost his hearing. So I did talk to him a little bit about it then and he's the same attitude as I have, okay you're deaf, but he's reasonably fit otherwise. You know, you've got to take the rough with the smooth haven't you?

(What did you say to him?)

I talked generally about it. I don't think my husband would have been interested in joining in the survey so I just mentioned to him the fact that I was filling it in and he's quite happy for me to do it. But I don't think he would have been that concerned about filling it in [for himself].

(What did he say to you?)

As I say, we do agree about these things. You know, we're not militant people, we're just grateful for what we've got really. Our quality of life is far better say than when I was younger, when I was a child, and you've got to look at that haven't you.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

As I say, we'd got these problems in the family at the time so it wasn't really appropriate to talk to my daughter about it because she was going through, you know, she had a mastectomy and then started the chemotherapy which was quite aggressive. She would have been probably someone I might have spoken to about it but the circumstances weren't fitting for me to actually do that.

(Why?)

I think we're quite close and she always says "you and Dad do well" which we feel we do.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, I wouldn't have said so, no.

Q8 What could we have provided that might have helped you to better use the information you were given?

No, I think, you know, it was just something that I did. I filled it in as honestly as I could. I was asked to do it – I think it came through the doctor didn't it? So I felt, well, I always feel that, you know, it's better to help. I went on a study a while ago because I've got a family history of breast cancer. And I didn't know what I was taking, and it was tamoxifen actually I took for five years. So I felt that, perhaps, that would help my granddaughters maybe in time be able to take something that prevented them getting cancer. I looked at this survey in the same manner. If you can help other people and help yourself, that's what we're all about isn't it?

Q9 Do you think QoL information would be useful to share with a Health Professional?

Well I think it is because I think that is a good indication of how fit you are and your view on how you treat any illnesses. It's your attitude isn't it sometimes towards illness. Sometimes, you know, if you sit in a chair and not do anything. Sometimes I ache when I've been out on the golf course but I feel, well at least I've walked the six miles and it's what's keeping me reasonably active. You know yourself, say you've had an operation and you can't walk and I've sat in a chair, and I get worse. I get really achy. I think a lot of it is attitude of mind as well.

Q10 What would you want a Health Professional to do with that information?

Well to maybe understand other patients so that they can talk to them. If you share it, it's a lot less onerous isn't it?

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes, I'm sure. If it's a lonely person, never seeing anyone, as you've just been seeing on the news now, it must be terrible if they don't feel well. I'm sure they feel even worse because nobody calls and nobody chats with them.

(Do you think it's helpful then for HP's to understand the bigger picture?)

My doctor does talk. I talked to him not long ago about the situation I was in and that I sometimes get upset and he said, "well, it's only natural that you would be upset, you're a mother". And my brother was very close to me and he died last September which absolutely threw me completely. Normally I'm not an emotional person but as you get older you realise your mortality, if you like.

You've got to do the best you can for yourself and I think doctors need to put that over to patients. You know, it's up to them isn't it, you know, to try and make their life better, if it's walking or joining in, or going to some meetings or joining some society or... It must be terrible if you're on your own and you've no family or the family live away and you never see anyone, and all they're doing is sitting, maybe watching television and no-one calls, it must be awful.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

Yes, I think it did, yes [make a positive difference]. We've both worked hard through our careers so the pensions we've got are what we paid into, let's put it that way. Looking back as a child brought up in Yorkshire, we weren't that well off. But we've a far better quality of life and you realise that when you're looking at feedback and things. You appreciate what you have.

Other comments

I do think that sharing with professionals, you know, nursing or doctors, that does help. I think a lot of it's attitude of mind. I've seen illness and, if you can approach it in a positive manner, which my daughter has approached this breast cancer she had, a very positive manner – she's probably done better than I have with it. I've been really quite traumatised by it all.

If people can approach things like that I'm sure it helps. I do believe that a lot of illness is caused through people, through stress and various things that happen in your life.... If you can be more positive and if the professionals can help you to be more positive, you know, by talking about things they know from other people. I don't think people like being pointed out that they should do this, that and the other, but I do think that an overall picture is. I think if you can realise that you're not the worst off in the world, that there are other people in a similar situation to how you are and they're coping, maybe it would help. Just saying you need to get on with it, and you don't feel like that, that doesn't help at all does it? I think [to be given] a bigger picture is far better than a doctor lecturing as saying you shouldn't be doing this and you should be doing that. And they may find it very difficult to do what the doctor's saying because of circumstances of living on their own or whatever. You know, and to get out and meet people, it's very difficult if you've not done it for a long time or to go and join something on your own. And to maybe give them some information about groups they could join. The feedback helped a little and just filling it in made me realise that perhaps things are a lot better than I really thought. It just focused your mind on what the quality of your life was. Life goes on and everything's fine until you get something like illness and we've had two in one year that really throws you doesn't it? Before that you don't realise that things are going along pretty well.

P62 [05]

Wednesday 22nd June, 2011 3.30 pm – 3.56 pm

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

I suppose 5 minutes or so.

(Prompt – less than 5, or 5-10?)

5-10 minutes I suppose.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

I don't think I have really because I probably made up my mind when I did it and when I received the graphs and when I looked at them afterwards, and.. a lot of the things I don't think I could change anyway.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No, I think I put them away in my drawer.

Q4 Did you show the graphs to anyone?

No

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No, not really because I don't think they will be interested.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

I haven't the most idea. Probably not with my family because I don't think they would be interested. They would probably think "why are you doing this, you can't make any difference".

I might discuss it with, mm, no, I don't know if I would, because I know people's reactions to...

(would that be with somebody else?)

Yes, with a friend or something.

They'd either [be] picking on it excessively, or you know, you must do this, and I don't like being told what to do. I suppose, from what I can remember now of what I did, a lot of the things you can't change and I don't know if they're entirely relevant to my picture of me, you know, my health, my social position, my psychological health and all the rest of it.

Q7 Was there anything at all that you did as a result of looking at the graphs?

Not particularly because of doing that. I do my actions and make changes [anyway] for my benefit, sort of thing.

(How would the quality of life feedback, or the questions you were asked, assist you in making those changes?)

I suppose I thought in a way, some of them, that perhaps things are not overall as bad as you think they are, if you break it down. I was just trying to think what some of the questions were

(Some of them were about how satisfied you are with...)

Yes, about how satisfied you were and how lonely you were, but it was very specific for at that moment, or the last few days.

(Yes, you were asked to talk about how you saw your quality of life over the previous two weeks, so it was very sort of time specific, you're right.)

It was, whereas I don't know if you can make it as specific as that. Well I can't anyway because I think things that make me sad or unhappy are long term and you can't often do anything about them because they're because my husband's died so you get a sort of continual loneliness which is not affected by who else you're with or where you are. And I mean, sort of, about, sort of long term regrets for things you've done in the past where you've treated other people, which you can't do anything about.

Q8 What could we have provided that might have helped you to better use the information you were given?

I don't know. I suppose, oh I suppose I should have looked at it. I still think it wasn't specifically relevant to me.

(Prompt:)

Probably some follow up. I suppose with another health professional that I could make my views known to as well, because I'm vaguely dissatisfied with the way everything is going because they're not giving people what they want in any direction – people of my age group. I suppose my future is absolute fear and dread because continually on the news, continually from everywhere is how awful treatment is in hospitals, care homes and even in your own home. Time and time again, news, television, it's blasted out twenty-four hours a day. And almost blaming an older generation for being old. I've been getting to this age for quite some considerable time, I didn't suddenly appear! Suddenly somebody found, gosh, you know!

Q9 Do you think QoL information would be useful to share with a Health Professional?

I think it would. I think they're all on the wrong track. Because I go to a luncheon club and we have talks by different health professionals and they dole out their leaflets, and we're all

sat there giggling because we could have come away completely and utterly depressed because [we're told] "do not open the door, because somebody awful is there: do not answer the phone, it's a scam; do not go in the street because somebody will knock you over" so you're absolutely terrified. It raises all the fears and I think, well, if I've got to this age by eating what I eat and going where I go, I should be able to take care of myself to some degree. I know I'm slower and I hate being called vulnerable. I think fragile is better. "The elderly vulnerable!" There's so much jargon about everything – I was saying to somebody, "if I sit in front of my television watching Wimbledon, eating strawberries and cream, I don't want to think this is five-a-day and I should have low fat yogurt instead! It's strawberries and cream!"

Q10 What would you want a Health Professional to do with that information?

Well try and think more... stop thinking of my age group as a set thing that's in the past. I don't go back any farther, music-wise, than Elvis Presley and The Beatles. I don't want to sing Daisy Daisy - I absolutely refuse! If you're going to do boring exercises...

(So do you think it would enable them to think about you on a more personal level?)

I think it would because I did have a health professional because I said my balance is bad and ... she came out with zumba gold. So I'm going to a zumba class. It is for the over fifties and "less able" and we all stand there and flap our arms and legs about and scream with laughter.

(Laughter is the best medicine they say!)

Of course it is but they sort of take themselves so seriously.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes I do. As I say if I never wanted to play bingo I'm not going to want to start now. And if I never did crosswords and all these other things why should you. If you don't do things at 20, 30, 40, why should you do them afterwards? But I think [health professionals giving talks to the luncheon club] were so stuck in a box it was easier, and they've got all their literature and all their programmes and they don't want to change it. And they've thrown them, they don't know what to do. You'll sit here and you'll do this that and the other because it's prescribed. But you don't go walking, swimming, dancing just for your exercise thing do you, improve your co-ordination?

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I don't know.

(Prompt: we've talked about health professionals perhaps using that type of approach to personalise things a little bit more in terms of advice....)

But do you think putting people into graphs does personalise it?

(Well, I think the graphs that you had were graphs showing you only how you responded to the questionnaires.)

But at a particular time and to your questions, that was the other thing.

(Do you think the questions perhaps then possibly constrained what you would have wanted to say?)

Yes, probably. I think society's so set upon everybody's physical needs or not, they... provided you're not too poor, too uncomfortable, too anything else, it's more personal relationships and interests that you miss [being able to talk about] more than anything else.

(Do you think the sort of graphs you had would be a way of initiating a conversation, that you could then be able to express more about how things were for you?)

I probably could, yes, I mean it if health professionals want to look at something then I could say "well, you know, this is not on, this is off, I want more of this, that and the other." That would probably help. [But] a lot of the things I don't think I could do anything about, or I've probably already done them or decided that I cannot do any more about it. Because there aren't the facilities and things that I would like. A lot of people are lonely and the other thing is transport – getting places. I think that's the other main problem,

getting to places that you would want to be or perhaps they're not even in the area. And you can't always move at that stage in your life.

I mean, you might have moved somewhere, as I did, because of your children, husband, work and all that sort of business and then all of sudden, that all changes. But you can't necessarily move somewhere else. I can't have a flat in London or whatever, you know? And the other thing is now, everything has to be paid for – I notice even with social service care, for carers, your family can't care for you and be paid can they? Which is ridiculous because, probably because your daughter or your family will care for you and want to, and why shouldn't they have money to cover the costs of their transport and everything else? And a lot of people won't have a carer because they don't want a stranger in their house. You don't want somebody else washing you.

And you don't want somebody else doddling though your laundry and things.

I know they're [government] saying you can handle your finances to pay for your care if it's subscribed who you can get it from.

Other comments

There are constraints and things that you become adjusted to, that I probably accept and don't notice.

I get frustrated when I can't do something that I want to do, because my hands are stiff or something like that.

And pain, and things, are very variable – I'm not in continual pain.

Helpfulness

(You suggested when you completed the study that you would find it helpful 3months and 3months plus. Do you think that's still the case?)

Well I haven't really looked at them because I think you just get on with your life as it is and you don't necessarily reflect "oh I could, perhaps I could do this" because you do whatever it is as of the day, or the week, or looking ahead as events occur. It depends on your condition. If you were very bad, or severely handicapped, you'd have to do more long-term planning. I just think at the moment I'm getting out while the weather is nice, and good, and sunny. And wondering what on earth I'm going to do in the winter. But there's no forward planning that I can do for that really.

It's according to what transport is available and where I can go. I think I've probably got to the stage where I have done all my planning and I can do very little now except for day-to-day, week-to-week, where do I want to go, what do I want to do, can I do it? It's no good thinking "oh well I'll move [to] so-and-so, or go abroad or take up another thing." Even taking up other interests are quite limited either because of access or because you're slower. There are things I would quite like to do, like I do not use a computer, but I have done some of the computer classes the government wants everybody to do. [But] it's cost again, because all these things are big packages. I can use the ones in the library but all I would do is Google information and can I get it elsewhere and easier? It's fun, but I don't think I want to be there all day. If it's a good thing or a bad thing – am I missing anything? The pace of change is so great, people are being left more and more behind and made to feel incompetent because of that. Then there are a lot of people who are physically unable because of their eyesight and their hands, to use this. I think I should stick up for them. No, I'm not going to do online banking! I want to talk to a person please!

Other

I think we're still the same people we always were but we're just slower and need a bit more time and things like that. But we still like doing mainly the same things as we always did and it's just not always possible. And there are so many things in your life that you cannot change. I'm sorry I haven't looked at your graphs, they're in my drawer! I think I probably will look at them in time, well can I do anything about that or that or not. Perhaps I could look at it slightly differently but I don't think it made an overall difference. But perhaps that's just me.

P66 [06]

Thursday 23rd June, 2011

9.30 am – 9.45 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Probably about 20 minutes / half an hour.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

Not since then really. They haven't been at the forefront of my mind, no.

Q3 Did you look at the graphs again after you had finished taking part in the study?

Not since our chat and a quick 20 minutes, say half an hour afterwards, no.

Q4 Did you show the graphs to anyone?

No

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

I don't think I've got anyone in mind.

(Is there a reason why you would want to not share them with anyone else?)

No, I just thought it was a discussion between you and me.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, but perhaps to be a little more positive in my thinking towards life in general rather than matter of fact.

(So it changed your perspective a little bit?)

A little bit. It just made me aware of things when I did things, or within a certain state of mind or mood I suppose, yes, there were slight reflections on what the graph and the information had shown me.

(So it did help you in that way in terms of giving you a slightly different picture possibly).

Well, not helped me, but made me aware I think, and possibly helped as well.

Q8 What could we have provided that might have helped you to better use the information you were given?

I thought it was very well presented, so I really couldn't comment on that, no.

(After prompts with examples:)

An action plan, now, I could see that could be useful to some people. Whether it would be useful to me or not, I'm not sure. I'm not sure I was prepared to take any actions quite honestly.

Q9 Do you think QoL information would be useful to share with a Health Professional?

I think it could be. I think in my case, the way I operate, I think that would be more useful for me to discuss with a health professional than a spouse or friend or partner.

Q10 What would you want a Health Professional to do with that information?

Well, if there was a need for some sort of intervention or treatment I suppose - I'm thinking of psychological matters. I think, you know, the questions, the information, could have opened up certain areas of interest, for both the individual and the professional medical person.

(Reminded of domains of quality of life)

Yes, and I think many of those topics would be useful to a professional who is trying to assist an individual in some way.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

(Useful for HPs to be more aware of how their patients see QoL?)

I should think, in many circumstances, that would be the case, if the health professional has got the time! To go into it in that depth, rather than prescribe a pill or psychologically say, “go away and pull up your socks” as it were.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

Now you’ve raised that question, I think I might be tempted to go back and look at the graphs again, and use it as an “aide memoire” or reference document. When, let’s say for example, I find myself in a certain mood or set of circumstances, and you have a reaction, or feeling, or an emotion, it might be worth, out of interest or perhaps the need of help, to refer back to them.

It could be a reasonable reference document.

(Do you think it’s something that possibly has potential to be repeated or would you do it as a one-off snapshot?)

I’m fairly ambivalent about that. If I was prompted to do it in the future I would have no reason not to do it, it sounded quite interesting. There’s no reason that I would say, “no, I wouldn’t do it again”.

(But you wouldn’t actively seek to do it to chart changes across the lifecourse or something like that?)

Not unless something significant has happened or changed. But you may be talking to me and I might be a quirky individual! I don’t know that, but some people are far more, I think, open about their feelings and emotions and attitudes than perhaps I am.

Other

I just found it of interest that this area of exploration, it that’s the right term, is underway at the moment. It’s something I would not have, well, I have no reason to things on these things, it wouldn’t have occurred to me. And I think, for some individuals who have got a more vivid imagination, stretching towards hypochondria or what have you, might be prompted to think that there are things more, well, affecting their lives than they really are. It could be a catalyst to think many things are wrong psychologically or physically.

(So there’s a cautionary note as well?)

I think it’s horses for courses quite honestly. I have a number of friends who, if the wind blows in the wrong direction, there’s something wrong, you know, that sort of thing. And I’m not one of those!

Helpfulness

(You suggested in one of your responses on the questionnaires that you’d found the exercise somewhat helpful to you over both the short and longer term. Do you think that’s still the case?)

I do, but I think, what I’ve said before, is that now we’ve opened this discussion I think I might be prompted to go back and read it again. Because it, I won’t say it answered some questions, but it gave me a different perspective on things that were happening or have happened, or experiences I’ve had and it just made me think about them a little more sensibly and in a linked fashion.

(So would you say from that, that actually one thing we possibly could do is, that when people have done something like done the surveys and had the feedback, we give them a prompt in two or three months and say “do you want to go back and have another look?”)

Yes, dust it off and re-read it. Yeah, I think there's merit in that. [Mine] have been gathering dust in a drawer but I mean to keep them for, I suppose, as long as I fancy, but I think this conversation will prompt me to look at them again.

(So giving people a second prompt, that's another approach we can use.)

Or just tell them, "try reading them every three months or six months".

Because I must admit, I didn't commit all the graphs and questions to memory, so it's just an overall feeling, impression, I'm talking about now.

P61 [07]

Thursday 23rd June, 2011

10.30 am – 10.46 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

I would have said, roughly about 20 minutes.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

No, I haven't given it any deep thought since because I thought that really was the end of the story.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No

Q4 Did you show the graphs to anyone?

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

Oh, I would probably do that with my wife. After 53 years, yes. We tend to share most things.

There's always a degree of consultation if there's not a yes/no.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, I looked back at it and it was really, a sort of um, in my mind, it was like a summary of my life. It was very useful [at the time]. I may have fed it in. I would say, in all probability, that was fed into the brain and that, like most things, especially as I'm deeply religious, that I would use that, yes. I think it was like pulling the reins up and not stopping the horse really, but it was a caution and there was an awful lot of good in it. It was like a profile.

Q8 What could we have provided that might have helped you to better use the information you were given?

I think if one could have a summary of it, it would help for future reference. Because with the memory and so much happening it's a good thing just to have a sign pointing in one direction and saying "look hold on a minute, look in that direction".

Q9 Do you think QoL information would be useful to share with a Health Professional?

I think it would, yes.

(Why?)

Because there are factors in there that one does not relate to a health professional so it's the sort of thing that you've got locked away but you don't really want to disclose it to anyone other than probably my wife. But it's a lot of useful information that could be used to one's betterment.

Q10 What would you want a Health Professional to do with that information?

Well I would say with, because I believe in life, different stages [of your life] you have a different outlook. I believe that having got this far, I would be able to speak to a health [professional] so that it could really affect others.

(Would you want them to use that information for you personally?)

I would have no objection to that because I'm very close to my doctor anyway. I think it's [about] getting a better view of what I am and where I'm going.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Certainly, because people don't talk anyway and I know, I've said I'm very close to my medical man, and people, they close up, they don't talk to their doctor.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I think if I had that graph 30, 40 year ago, it would have had a greater bearing on where I am today. I think that the earlier you start this, the better.

(How do you think it would it have made a difference if you'd done it 30, 40 years ago?)

I don't know but I certainly would have questioned a lot of the decisions that I did make.

(Do you think it's something it would be useful to repeat every so often?)

Oh, I would say so yes.

Other

I felt at the beginning of the questionnaire and towards the end of the questionnaire and all the questions that were asked I felt that I was getting a picture of who I am, what I am, and I could use that for the future.

(So it wasn't just the feedback you were given, it was actually the process of completing the questionnaire?)

Absolutely.

(And you think that type of information, that type of process could be useful for other people as well?)

Oh yes. But then we're all very different. I am a sort of open person, and I'm open to anything that will better my life.

Helpfulness – you indicated that you found it helpful?

Oh yes, more so, I wish I could have had a lot of those questions thrown at me at the time because I made some very big decisions and affected other people and it could well have clarified the situation and probably it could have been for the worse, but it could have been for the betterment.

I think the questions asked and the end result was that they would lead you to making better decisions.

(You didn't have the opportunity to do it 30, 40 years ago but you did it a few months ago. Has it made a difference for you now?)

In my thinking, yes. If I'm going into something now I hold up and I say "now let's analyse this, let's just look at it in different ways, not just one way".

(What are you hoping to do by doing that?)

I think, even at this stage in my life, it would enrich my thoughts and it would probably give me more indicators of the direction to go. And we're all built on decisions – we have to, all of us, no matter. Not always big ones but the small ones, and some of them are very explosive, some of them become very important. As a result of that, it makes you think more. You put the brakes on and you don't just go into something, you start thinking.

Other comments

I think it's a great pity that it's not broadened amongst a wider spectrum of people. I think, if I may say, it's probably touched on the few privileged, because they're privileged to have

done this. They're privileged to have the feedback from it. Because you fill in these questionnaires and you seldom get any feedback.

I would be happy to get further feedback from you.

(So for you, it's something that you might appreciate doing on a more regular basis?)

Yes.

(It's something we're thinking about, whether we can put this type of thing into GP surgeries so people can get more easy access.)

Oh that would be of great benefit. The doctor, I know, as he says people come to him and they become "Lock Jaw Lewis", they just won't talk about things and he or she has looked at their clock and they've got 20 minutes. If the doctor can pick this up [the graphs] and have a look at this, it would be of great assistance to them. I know for a fact that they [GPs] lack patient input, they have to ask questions all the time. I can tell you this much, and speaking from my heart, it's [the research study] very worthwhile. What you're doing is something that it's a great shame wasn't done twenty, thirty years ago. I think that people have been reluctant to take the lid off and talk freely about themselves.

P70 [08]

Thursday 23rd June, 2011

11.30 am – 11.53 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Well it is a long time ago but I think you said to look at the graphs before we did the second one...

(That's right)

...and I did that and I think one of the things that surprised me was to do with the meaning of life.

I somehow got myself saying that there was no meaning to life, and that was quite the opposite and I think I did phone you about it.

(That's right, yes you did, and we corrected that one because the question was a little confusing wasn't it?)

Well I was certainly confused!

(Yes, there was a question about "to what extent do you feel life to be meaningful?" and I think, once we'd clarified it, you said yes, it was meaningful.)

Because, as far as I'm concerned, I think I remember looking at the reports and the graphs and I saw that spirituality was quite low down and that was what alerted me to the fact that I must have said something completely wrong because spirituality, so far as I'm concerned, is very important.

(Yes, sometimes we just accidentally tick the wrong box don't we? But, yes, I remember that because, yes, I've actually got your paperwork in front of me, and originally, the question was "to what extent do you feel life to be meaningful?" and you'd indicated "not at all", and then we obviously corrected it because we changed it to "very much".)

(So how long do you think you spent looking at the graphs then before you did the second set of questions?)

Well, I suppose in order to take them in properly, it must have been about, I think, about 20 minutes.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

Well certainly, I mean, I'm moving into, probably, the role of carer because my husband has been diagnosed [as being] in the early stages of dementia. So from that point of view, life's uncertain, but then everybody's got uncertainty about the future, no matter what way. But I think from the point of view of the quality of life I have I'm very fortunate.

(Yes, so did the feedback make you think about that in any more detail?)

In detail, um, that's hard to remember actually. Yes, I find that rather hard to remember.

(That's fine and some people, they looked at the graphs, and looked at the feedback and then popped them in a drawer, and that was that, and other people had a different approach.)

I can't say that I put them in a drawer and forgot about them. It did make me, I suppose, assess different aspects of my life. I don't think I came up with any remarkable solutions for any possible problems that I might find I'm facing. I just accept the fact that I, really, have got a pretty good life really.

Q3 Did you look at the graphs again after you had finished taking part in the study?

Yes I did.

(How long did you look at them for, and when did you do that?)

Probably, I should think, about a month afterwards. I just didn't look at them for any length of time. I just looked at them really to remember what was said, which would probably have been about 5 minutes or something.

(Did you focus on any particular aspects?)

I think psychological health.

(And why was that?)

Well I think I was, again, I bit surprised that it was only, it was lower than physical health, because I feel that one's psychological health actually is a great contributor towards one's physical health. In fact, I think it's probably more important than one's physical health. One's attitude towards any depletion of one's own health is very important and if you've got a negative attitude towards it, it's probably going to make it worse. So I think psychological health really was something that I was quite surprised, that it was as low as it was.

(Yes, I've got your graphs in front of me, and certainly, in terms of importance, you'd rated that as lower than your physical health. So that was something you particularly wanted to have another look at?)

I wasn't quite sure on what basis it had been judged if you like. I don't know what criteria within the paper that I had answered was the deciding factor rather.

(Yes, because there was a whole barrage of questions, and it's not clear when you're completing them, which questions belong to which area of quality of life.)

Q4 Did you show the graphs to anyone?

No I didn't.

(Was there a reason why you chose not to do that?)

Well I would have only shown them to my husband and, in fact, I didn't necessarily want to. I mean, he asked what I'd been doing, and I said "Oh, it was a quality of life questionnaire" and he didn't manifest any interest in reading the answers so I didn't feel I should show them to him.

Q5 Did you discuss the information in the graphs with him?

No

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

I suppose I have a dear friend who's dying but then I wouldn't show them to her because she was dying and I wouldn't want to disturb her feelings about the quality of her own life. No, I don't think there is anybody.

Q7 Was there anything at all that you did as a result of looking at the graphs?

Well, certainly the spirituality I did find strange and obviously we did change that.

(Was there anything else in your life that you altered or you thought to change?)

I wasn't sure about the negative feelings because I don't think I understood the question properly because, to me, when I think about negative feelings I feel that they're very destructive and therefore I feel they're to be avoided. I don't mean to actually bury them, because that's not terribly good either. I think if one has a negative feeling one takes it out, looks at it, and sees that it's destructive, and eliminates it as much as one can. So negative

feelings are something that I feel have to be dealt with and only in that way are they important, that you deal with them and leave them behind.

(Yes, because what you'd said in your responses was that you were seldom troubled by negative feelings, but you didn't say that you were never troubled by them.)

No that's true.

Q8 What could we have provided that might have helped you to better use the information you were given?

Well it was very clear. I mean, apart from the slight confusion over the spirituality and the negative feelings. I thought it was pretty helpful. I don't know whether the formulation for the negative feelings could have been a little bit more crisp? Because maybe I read the graphs the wrong way because when I read them I thought how low spirituality was, it said very poor.

I've actually got my graphs out now, so I'm looking at them.

(It actually says, for spirituality, it says it's a number 4.)

Well, now it is! That's the resolved one! But it also says negative feelings...

(Right, that one's a confusion then because actually the higher the graph is – the higher the bar – the better your quality of life. So the higher your negative feelings bar, the fewer negative feelings you have.)

Right, so that confused me then.

Maybe that could be clarified if you plan to do it again with other people.

(That's true because there were actually three questions that were asked the wrong way around as it were. On the physical health graph, you've got "pain" and "medication" and then on the psychological graph you've got "negative feelings" and all of those are: the higher your blue bar, the better your quality of life. So, for example, the pain one, if you have a pain of 4 or five, that means you have very little pain. For most of the other one's it's exactly what it says so if your body image [bar] is high, it means you have a good body image. It's just those three: pain, medication and negative feelings, we have to reverse them and that's why it's a little bit unclear. Possibly what we might do is re-label it to say "free from negative feelings" or something, and then it would make more sense, because, actually you have a very positive score on that one! That's useful feedback for something we could do going forwards, definitely.)

(Is there anything else we could have provided, such as an extra leaflet or an action plan to complete, or some extra advice, that might have helped you to use the information to make some changes in some way?)

No, I think you were quite clear. I think that's okay. Apart from what we've said, I think everything else was pretty clear and understandable.

Q9 Do you think QoL information would be useful to share with a Health Professional?

You mean for me to share it?

(Well generally. Either for you or for somebody else.)

Probably it would.

(What do you think the benefit would be of doing that?)

Well presumably the health professional knows my situation and knows my husband's situation and therefore would be able to assess whether my own wellbeing is okay. In other words, he would be able to assess whether I was stressed, over-stressed, or whatever, by the situation I'm in. So yes, I think probably it would, which might be something that I could share with the doctor.

Q10 What would you want a Health Professional to do with that information?

Well, not necessarily anything unless I did become overwhelmed by any situation. I don't think he would necessarily have to do anything.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes.

(And you think that would be valuable...?)

Yes, I think it would.

(So how do you think that would affect people's treatments and that type of thing?)

Perhaps there would be - and by saying this I'm not saying that I don't get understanding from my own doctor - but maybe there would be more understanding by the professionals of any given situation. But they're probably overworked anyway, so maybe it wouldn't do anything!

Q12 Have you got any other ideas for how QoL feedback, like the graphs you were given, could make a positive difference to you?

Well I hadn't thought of this before but I was just thinking as we were talking that it might be quite useful if I put at least one of the graphs up so that I could glance at it now and again.

But not the overly detailed ones, just the more general one. ***(So that very first one that just has four bars for physical, psychological, social and environment?)***

Yes, just to see how I am. I mean, I don't want to get too introspective but it's quite useful to have a bar graph that you can compare yourself to.

(Yes, because we're thinking about how we can use this type of information really, and whether it's something that people might find useful to do on a regular basis or just do as a one-off interest.)

Well, I did find it quite interesting to do the second one, having done the first one. I did it as you asked, without reference to the first one and then after I'd done it I compared both and there were differences.

(So you went back and had another look?)

So when I'd done the second one I went back and had another look because I'd taken a copy of the first one, and I saw that there were differences. So that was interesting to me.

(And that's what we've really been looking at. To see where those differences are between the first time and the second time and you indicated that you'd like to get a summary of the results when we've processed all the data, which we're in the process of doing. Just to let you know, early indications suggest that where things change for people is that they feel a bit more positive in terms of their psychological health.)

Yes, I think that was probably on those lines. Perhaps because one's attention had been drawn to it by the first one, and therefore one was more aware of one's thoughts and actions.

(So perhaps it was actually the process of completing that had the effect or perhaps it was getting the graphs and having that opportunity to reflect back that had the effect?)

I don't know. I think the process of filling in those forms made one quite thoughtful about one's life. And some of the questions were more difficult than others, but that was good because it made you think harder.

(And receiving the graphs then...?)

Yes, that was an additional help.

(Well that's great. I'm glad you found it interesting and valuable for you. And thank you for all your suggestions today about other things we could do with it. It's really very important to us that people such as yourself are so accommodating in helping us and it's very much appreciated.)

Well it's been my pleasure because it has actually been an educational process for me.

I mean one doesn't always look at one's life in any great detail, so this was a great help in that respect.

Other: Do you have any final comments for me?

No, other than it was a helpful process and I just hope that it will be a more general helpful process for you in your study.

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

(Prompt: We spent some time on the phone going over your graphs, so there would be that time and I don't know if there was any more time you spent before you then went and looked at doing the second set of questionnaires?)

I didn't, because, not that you'll remember this, but I was very aware that my life had completely changed in the two or three weeks in between. I got work in, and the whole world turned round into where it used to be actually (laughs).

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

I have actually, because, and again, you may not remember all these details, you've got a lot of people to speak to, but I found it quite fascinating that I actually, because it was an anonymous survey probably, I was utterly honest, and when I got those graphs back it made me do a double take of my life and think "gosh, that is actually where you are". So it gave me the opportunity to evaluate where I was, and certainly when I did the second one, it was fascinating to see just how life had changed. In a very honest way.

(And did you think about that again after you'd done the second lot?)

Oh yes, very much so.

(How long did you spend thinking about it?)

It's something that keeps coming back to me actually. From my own experience and how this affects other people. And this is all a work-related thing of course, but actually, if you are without work for long enough, how your whole world is dimmed.

(So is that the primary part you think about, work and how it relates to other aspects of your life?)

Yes. I mean, it's never happened to me before and I was quite shocked at how, I don't want to say devastating, because it's a creeping feeling. But how it actually, I say dims, it just dims everything and life is very different.

(And when you say it keeps coming back to you, are there particular things that prompt that?)

It's probably listening to the news, seeing how many people are actually struggling to get work, particularly people of my age. And even if it's not financial, actually life at this age, without work, is for me, not on. And I just feel, and especially now with this pension thing and the pension age, and I'm caught up in it by a few days actually. And then that comes back to me and I think "gosh, if those people are actually not working today, and they're 50...". So it keeps, and that whole sort of thing about, and yeah, I see those graphs and I do see things in my mind's eye, I see those graphs.

Q3 Did you look at the graphs again after you had finished taking part in the study?

Twice actually.

(Right, and when about was that?)

I would say a few weeks later. Just to sort of check and see the difference actually. I mean, to labour the thing, the difference in those few weeks. I mean it's one of life's little gifts isn't it that you happened to pop up at that point, because I never would have been able to have had that same measure. So when I think back on it, I do think of those graphs, that's what sticks in my mind.

But I actually was, in my previous life, I actually was a merchandiser, a sort of form of business analysis, so you do a lot of graphs and pie charts and... So I do tend to see life in terms of charts.

(So when you looked at the graphs over those few weeks, did you look across the breadth of them or did you focus in on any particular aspect?)

I focused in on the difference.

(But across different areas – prompt – were there any particular aspects, when you looked back again, that you focused on?)

I would say physical health is not, I mean, I am probably creaking a bit, but for my age, it's not an issue so it's something that I don't actually think about. I take it for-granted really. Social relationships are fine. So it was the others that were actually the more, yeah...

(And the thoughts that you had at that time were around comparing where you'd got to, with where you'd been.)

Yes. And where I would expect to be. I think that's the other thing isn't it, it's managing expectations. And that's the other interesting thing with that survey, it's where you think you should be and where you are. Because that's what you do isn't it? It's the gap. Which for me is the big one, because actually, in lots of areas, I don't have huge expectations. I'm actually quite philosophical. But in other areas I am demanding to the point, which sounds awful, but actually, if I don't get what I want I'd think "well, I'll just pop off then." If my quality of life is impaired beyond, then I would want to go quite seriously. So it sounds dramatic, but that's how I view it.

I suppose it's the old thing isn't it, that you tend to sit into a pattern if you like, of behaviour or thought. So lots of things that matter to people hugely, for me are just, almost laughable, but then I suppose the other things, you know, being trapped in some sort of ill-health situation, without enough money... I'm certainly not bothered about dying but I'm very concerned about my quality of life, being impaired and being trapped in it. So I suppose, in that sense, quality of life is..., well it must be very important for everybody, but for me, it's of ultimate importance. If I can't reach the right level on that graph, then I don't want to be here.

Q4 Did you show the graphs to anyone?

I did.

Just one of my pals actually, but I'm not sure um, whether she quite... maybe she wasn't quite in the mood. And there's one other girl who I don't see very often actually, who lives in Devon, who's quite a bit older than me and I have spoken to her about it, because I am enthusiastic about it because it actually it was one of those things that but was very interesting to me and the timing was immaculate. So, yes I will actually show them to her at some point when I see her.

(But you've discussed them with her?)

Yes

(And what did you say to her about them?)

Well that it was fascinating, because I am fascinated by life I should say. But the timing actually, that you popped up at a point, and then when the second lot [of questionnaires] came, it was just either side of where I sat. And how helpful it had been because, actually, the first lot [of questionnaires], it made me really realise just how far down the line I'd slipped and I was pretending to everybody that life's alright, 'cos you do, but actually it really wasn't.

(Did you realise that at the point at which you were completing the questionnaires or the point at which you were looking at the graphs?)

As I completed the questionnaires. As I was about to lie (laughs)! I thought don't, don't do this.

And I suppose it's a dignity, pride, privacy, I don't know, what it is, but I find, very rarely, can I actually own up because I don't want people to think "oh, poor thing". But sometimes you need to.

(So contemplating the questions in some ways, had that moment of realisation for you?)

Well yes, it was quite jarring actually. Yes, it was, coor, this is where you actually sit, this is what's happened, something's got to give here. And I had thought of various avenues, but I thought I really must do something actually now proactive. Whether it's right or wrong I need to take some action because life is not, you know, I can't go on like this, because it isn't a proper life.

(And then, at that point after which you had that realisation, the gap between that, and receiving the graphs back and getting the second set of questionnaires, you say things had started to change for you?)

Well yes, I got two things: I got some consultancy work and landed a part-time job, which I was really, it sounds ridiculous, but that's more important, a couple of days a week which has transpired to be what I'd hoped it would be – it's brilliant for me. Yes, just again one of those things that you can't go and find, they just, sort of, pop up. Having contemplated any old sort of jobs, I'm dreading it, thinking "how has life got to this stage?" And, since then, another bit of consultancy. And I'm not really looking for that work now because I am actually, I worked in the fashion business, and I'm not far off 60 and there's a point where you are outside it. But it was to do with graduate recruitment so it's a different thing and it's interesting. It's just that sort of thing that, how life works isn't it? Something pops up that, and you feel your self-esteem. I think that's what had happened, my self-esteem had taken such a bashing. And it's probably happened, no, I don't think it had ever happened before actually. No, I think I had to learn a lot – a hard lesson!

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

(So just coming back to the graphs that you'd showed to one friend, and discussed with another, what did they say to you about them?)

Um, the one who hasn't seen the graphs, was quite fascinated. And I know she would love to do the same thing. But she and I do share a lot of this - she ran her own business and she's now in her mid 60's and she's very interested, if you like, in what happens to us as we age I think.

And because she's eight years beyond me, I can see myself following her, and I can see myself not understanding where she was coming from, particularly because she actually does have, this sounds awful, but plenty of money. So she hasn't got to worry about money. But as the years go by I can see exactly where she was – where I am now if you like.

The other one, interestingly, is seven years younger, so we're not, not a whole generation, but there's a big gap between these two. And we all used to live in Bath around each other, so we all spent quite a lot of time together, but it is quite interesting to see how the one who's much younger, I don't think was really getting it at all actually. I don't think it's something that she considers.

(On an academic level or in terms of understanding the picture that it gave her of you?)

I think the academic level actually. I don't know what your findings are, but I think maybe we fall into two camps and perhaps we do polarise, but people who are, and I would, sorry, I'm fascinated by this subject, but a lot of people won't, they just, maybe they can't, grasp it?

They're just not, it's not of interest, and also perhaps it's a bit like philosophy – that if you don't actually, and I've just done courses up at the Uni, I'm not, don't get me wrong (laughs)! If you don't pursue these things, and talk about these things then I'm sure it sounds like Chinese. Like a lot of people think it's navel gazing and all that sort of stuff which actually, until it happens to people, I mean, it's seriously not.

And also I think of one of my sisters, or both my sisters actually, and one's probably on the autistic spectrum – she's quite unusual. And the other one, full-on career, just a couple of years younger than me, it's almost impossible to encourage her to talk about her, herself. And it just, every now and again there's a bit of a crisis and she is, we are, very close but she just doesn't. Just has that sort of personality that she doesn't want to show. My father says "show no sign of weakness". She's a real leader type, and it's that, and I think strong leaders are like this, I can't, and I'm a bit like it, oh I don't want to own up to feeling a bit fed up, but this is more than that it's almost, I can't say they don't know themselves, but they don't want to share what they know about themselves with anyone else, it's all tucked away. And so far I think actually they, I think they find it quite difficult to access.

But actually, I mean some people, what do they call it - feeding off their own emotions, who are so wrapped up with themselves they can't get out. It's like a circle isn't it? And then, if you like, the other extreme who never talk about themselves and actually, every now and again, when the crisis comes, it's quite difficult for them because they don't know how to deal with it. They don't have the relationships where you can pick the phone up and say "it's not just something's gone wrong, it's I'm really not quite". Well, I suppose perhaps that's where they go to therapists because it's private.

Q6 If you had the opportunity is there anyone else you want to show the graphs to, or discuss them with, do you think?

I probably, it sound quite unusual, but I do have, partly because I sort of help him out a bit, quite a close relationship with my father. And he's an engineer but he's a thinker – well engineers are thinkers but he's also very interested in talking to me about behaviour. I think he finds my sort of whitherings quite interesting, let's put it like that. So yes, and I haven't, probably because of circumstances at the time and then life moved on and I did become quite busy.

(But you think he'd be interested?)

Well yes, and he'd be interested in, he's interested in everything actually, I don't know if you know about these, I call them "engineer types" – they are seekers of information. So it doesn't matter what it is, and you can see sometimes they're a bit mystified when it gets a bit, sort of, too close to all the emotions. It's a bit like, "whoo I'm not sure about this". But yes, he would be, and he's very interested in academic study. He's not an academic but, yeah. These people with, it's either the type of mind or the intellectual capacity isn't it. He's got intellectual capacity and he's at an age, well he's 84, so he's interested in anything that comes his way.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, but I actually believe had the two lots of work, had they not turned up – and they came within two days of each other –... then I would have taken some serious action. I would have considered renting out my house and, I won't say going off, [but] doing something to actually get myself from underneath. Well I would have rented the house, lived with my father, and gone off and done, I don't know, voluntary work somewhere, something that had some substance and some meaning, because it was, for me, it was a life living in a ball of cotton wool without any true direction, and an underlying financial worry that the money's going to run out. And also it made me realise that I was actually really very unhappy, I think that was the bit that was the most striking.

(Which you wouldn't otherwise necessarily have recognised?)

Well I think you battle on, you don't want to give in to it do you? I say you, I think human nature is such that we resist it because we do feel if we give in we're lost. But interestingly....the thing that was most interesting to me was how it brought it home to me "you really are in a bit of a mess here"! (laughs) This is not where you wanted to be at all. I think it's that thing isn't it, I suppose it's like the alcoholic, until he wakes up in the gutter at 2 o'clock in the morning, or whatever happens, they go to a point don't they, they say people have to actually fall so far before they actually stand up and say "I've really got to deal with this." So I was actually bumbling along and bumbling along and thinking slowly but surely, well actually, I don't want to think any further because I'm going to become dep. I assume the next stage is depression. And I'm certainly not about to go and take some pills. No I wouldn't, you know, I can't believe that would be the right thing for someone like me. It's more a case of, right well, take a jump off a cliff then and see what happens, I'm sure something will come along. And suddenly it did, but there you go.

Q8 What could we have provided that might have helped you to better use the information you were given?

Not for me personally but I suspect, it's as you say, the people that will do these things tend to be interested anyway.

(Prompt)

Actually that, yes, perhaps if there's something that can be spurted out of a computer, that if it sees a big enough gap, and I know it's a bit set piece but, you know, you should, not should, consider taking some actions, consider yes those things you've just said [action plan, discussion with GP etc] because actually the result of this is such that things are... And especially if there were options, you know, sort of "there's a big gap here" I don't know "in our experience there are five routes out of this". And I think worded, I'm just thinking of whether people would think "how on earth can they possibly say this from something generated by a computer?", but it's a response isn't it.

Q9 Do you think QoL information would be useful to share with a Health Professional?

I would hope so.

(And what would you hope to get out of that?)

Do you mean a GP?

(Or a Practice Nurse or...)

I think a Practice Nurse is often better. I think GPs are (sighs) very good with the body and they're very good at actually looking at all the signs and pointing you off in the direction, which is their job isn't it these days? But in my experience, I don't think they, they haven't, I don't know whether they get close to, or, maybe I've never been to one with a problem "of the mind!"

Whereas a nurse, I think, tends to be, if ever I've had, and I've had my blood tested every year because I have a thyroid thing, and the nurses always seem to sort of have a bit of a chat and there's a different way about them. I think they have a much higher level of empathy. I think a lot of GPs don't, in my experience, ooh, what am I saying?

Q10 What would you want a Health Professional to do with that information?

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Very much so. I think particularly doctors because I do think a lot of time is wasted, people going – what do they say "25% of visits to the doctor are not necessary" medically, but they are psychologically. People are actually, and we all do it, you know when you're really a bit far down every little twinge – ooh, ooh. And I actually do, partly because I believe in the subject, but I actually think GPs should have, with today's world, the stresses and the way we live today, have more training in your [the researcher's] world. And whatever route they might use, some sort of ability to spot the personality type. I know they do it to a degree, they must do, and I don't mean the manic depressive or the whatever, but actually see the people that won't share. In that ten minutes is there a way that they can actually catch that, because a lot of people don't? Or if you're brushed off because, I mean, it happened to me and I ended up in bloody hospital last year which was all the beginning of my demise really. She thought I had, I can't remember what it was, I don't know, but I didn't say much and just kept joking about, because I do, but in fact actually something was wrong. But I really didn't want to know. So it's catching those sorts of things with the people that possibly do go but don't, you know, [who] make light of it all.

Well my concern for them is, they have these 10 minute slots and they're desperately trying to get through the day, and they have got people who've got serious problems. So if somebody isn't on their knees and jokes and says "actually I've got this sort of pain and it's running down my leg and, well, you know but I'm still working and da de da." They're not going to ask as many questions perhaps. And I do think it is a personality thing and you could track it back but whether that's, I don't know, do GPs have any training of this sort? I also think that actually sometimes the worried well could be, and I know therapy is very expensive, but you could nip a lot of this in the bud, because I think we can make ourselves ill. We can certainly, we can drag ourselves down and then of course our systems don't work properly and we catch all these things. But, it's the old thing isn't it, of actually how much money do you spend? It's preventative I suppose.

(So if you trotted along with the graphs, such as you had, do you think that would be helpful in terms of signposting people to those types of intervention?)

Yes, because also they could ask the question. And especially if they've got persistent returners or whatever you call them – people who are always catching things, getting things. And again you see, I suppose it depends perhaps GPs believe you just catch germs. I actually [think] completely it's mind-body. I suppose that's where I'm coming from, that I'm very much of that camp which...

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I think if you were to run trials or whatever and find people who had huge gaps... well it would point people to actually seek help.

(So using it as a sort of flagging up system?)

Yes, which is probably what happened to me. It was, wow! So I think for a lot of us who don't want to recognise, maybe the working mother with children and she's just battling on and battling on, but actually, even if it's that private moment that says actually something's got to give here.

And also because it's actually personal and confidential you can be very honest and I think actually, probably, the working mother who's battling, would then take 5 and say "should I be doing this? What's happened to my life, because actually I'm really not very happy?" But she won't probably because she's so busy and the demands on her are such that she won't allow herself to stop and think about all that. Because there are routes out of all these things. But because society has told everybody "actually what you need is a nice house and two cars", some people say "I can't possibly!" Well of course, they can in the end, because they make themselves ill. And that's what we often need, I needed it in my twenties when a doctor said to me when I had bronchitis "If you keep on..." well, he said it in a very clever way, about his son's girlfriend, and I'm sure she didn't even exist "basically you're actually worn out, you can't keep this up". I just happened to go, and catch a locum doctor who was probably in his 60's who just had the time and whatever, and also I was just worn out, completely stressed out with jobs and dadadadada.

But I was not going to recognise that. But if I'd been asked by the doctor to fill in a thing and looked and went "actually you know...". Also it's very difficult to give people advice when they don't want to hear it. You know, you can't really. But if you've got something in front of you that they have filled in, that says actually this is your life... That's probably actually, for me, the most important thing, that actually they have filled it in, and that's where they see it. And it's not the mood you're in when somebody asks you the questions, it's actually you do this form. And I do think when we sit down quietly and fill our forms in you know, we do think. And it's a very easy form to fill in. It's not asking you to think, in fact you probably shouldn't think too hard should you? And I'm also being very female focused, but actually, thinking about it men are probably even worse, because they don't chat to each other. Women do chat to each other and share their woes, men don't.

Other

It's been very interesting... thank you really.

P49 [11]

Tuesday 28th June, 2011

7.00 pm – 7.19 pm

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

I don't know in time-wise but I did spend quite some time sort of looking at them and thinking about it.

(Prompt)

Oh, I'd have said about 10 minutes probably. If anything, probably a little bit more than, certainly it was thought-provoking.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

I have, err, I have, but it was not long after we did the study. I must say I haven't thought about it so much recently.

(So roughly how long after do you think?)

Probably within a few weeks.

(And for how long did you spend thinking about it?)

Well I tend to ponder things quite a lot so I sort of go back and worry at it. I would say, probably on and off, maybe about an hour, if you add it all up.

(Was there anything specific that you thought about?)

I actually thought about the spiritual side of it and I was thinking how you made it break into pieces so that you actually could analyse it, because it's [overall quality of life] something that goes on in your life all the time, but when you break it up like your study did, it sort of, actually makes you think about different little areas.

(And were there any specific areas that stood out for you?)

Well, as I said, the main one was the spiritual one which I hadn't, something I hadn't really thought about for some time.

Q3 Did you look at the graphs again after you had finished taking part in the study?

I did once, yes.

(And again, how long was that after the study was completed?)

Probably about a couple of weeks afterwards.

(And again, was there any particular reason why you did that – you chose to get them out again?)

I think it was just to sort of clarify what I'd actually said was right, if you see what I mean. That I wasn't getting muddled up with what I had thought.

(And when you looked at those graphs again, did you focus on any particular aspects?)

No, I can't say I really did, it was just an overall looking through them.

(And did you have any new thoughts when you revisited them?)

No, not really. As I say, I just started thinking on from, if you like, the pointers that you'd given me.

Q4 Did you show the graphs to anyone?

No

(Was there any reason why you chose not to do that?)

It didn't cross my mind. I mean the only other person I would show it to is my husband.

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

We did talk about some things. I did talk with my husband about several things and he did to me as well.

(What did you talk about?)

Well we talked about that you were looking at old age and mobility and managing as you get older and as you get less mobile and that was something, I think because of my background, I think was something that strikes home more perhaps for me than it does for people that haven't experienced working with old people. And we did talk quite a lot actually about that and the house, and the garden, and things like that and how we could maybe think about that in the future.

(What was his [your husband's] view on what you told him about the graphs?)

I think we pretty much agreed to be honest. As I say, I don't know if you know, but we had a care home. So of course we worked sort of, he did the admin side and I did the care side, so he had an insight as well, so I think we pretty much agreed on things, it was just, perhaps, what shall I say, if I say planned it sounds very like we're getting old very quickly! If I say we were planning it, that before it's something you don't tend to think about, you think "well actually I need to, sort of, get, you know think maybe 5, 10 years, 15

years, whatever, we need to be thinking about this and sorting it out and getting it organised” rather than waiting ‘til the time comes and then finding, you know, that we are immobile or something and we can’t do this, or we won’t be able to do that.

(So do you think it was the feedback that prompted you to enter into that planning type process?)

Absolutely, yes.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

I don’t know that I would want to necessarily show them to anybody else as such but if I found that I would, if I said, I found I had a problem I think the graphs were very good at concentrating on the actual area, because it broke it down into different sections. I think if I had a, sort of, problem, I would be able to possibly use that if I went to see my doctor or something like that.

(What I’m interested in is knowing where would people take these things if they had the opportunity?)

I think it would have to be someone professional like that really.

Q7 Was there anything else [in addition to the planning mentioned above] that you did as a result taking part in the study or having that feedback in the graphs?

Not really, no, I don’t think.

Q8 What could we have provided that might have helped you to better use the information you were given?

No, I thought it was very clear and the way it was broken down was very clear and, no, I think it was very good.

(Prompt)

It depends what people are answering. For myself I don’t think, I mean, it might have been nice to have maybe someone who would ring up, a call, but I wouldn’t be able to tell you specifically what because I didn’t feel that I needed necessarily to say something to anybody else. The only thing I would say about a call was, I mean, I found it a really good tool but I did think, as a tool for someone like say a doctor or something, if they had it in a surgery to give people, a sort of maybe, views maybe, just to help clarify things, but I think it’s a very long thing for somebody to do quickly.

(In terms of the doctor looking at that information and picking out the main pieces?)

I think in terms of the doctor giving something to somebody because they’re worried about something but they maybe can’t either articulate it or put their finger on it. But somebody’s not going to sit for half an hour or whatever it takes to fill out the form, but if there was something maybe a bit more abridged, a bit more quickly. We just, both of us, felt it was a really good tool.

(Explanation given that feedback related to only first two elements of questionnaire set – WHOQOL BREF & Importance. ...If it were just those two bits?)

That would be fine probably, because it wouldn’t take somebody too long to actually sit and do that. But what I thought was very good about it all was the fact that it actually broke things into little pieces and that made you actually then to look at all the individual little pieces. You know, it’s what you do every day and what you experience every day but to break it down into those little, sort of, chunks and to be able for you to look at it and to look at the different facets of it, I thought that was very useful.

Q9 Do you think QoL information would be useful to share with a Health Professional?

Yes, I do. Yes because I mean, as I say, you’re dealing with things, and err, you do just do it almost on a subconscious level, you just automatically sort of do things and act on things, and, you know, think things but you don’t necessarily sit down and think “right, you know, let me think about this, this is fine” and so on. So I think, you know, for that, sort of, it’s a very good tool.

Q10 What would you want a Health Professional to do with that information?

I think if they could do it when they joined the surgery or something, I think it would give the doctor a baseline and I think then if there are problems, I mean, whether psychological or physical problems, they've got a baseline to go, because I mean, obviously different people think different things and have different levels of pain, mobility whatever, and what they think is acceptable, I mean, what I think is acceptable, might not be acceptable to you or my doctor or you know. So I think it provides a baseline and then if there is a problem the doctor could maybe almost give them the same thing again and if they can't articulate it, if they can't pinpoint what the problem is, it would help to, sort of, narrow down the areas between the two of them.

Yes, I mean, again if there's people with like, I deal with a lot of people at the moment with psychological and mental problems and for somebody like that, that would be a fantastic tool to judge the up and downs and what they're thinking and where they're at. I mean you could almost do it, like, when people go into hospital and that sort of thing. Again it gives them a baseline to work with because I think that's the difficulty because everyone's individual, to have a sounding board that that is how that person views things and that's how it is and then, you know "you can improve on that" or "that's the area you need to concentrate on" or whatever. As I say it does make you, well it does me anyway, I think the majority of people think about the little compartments as it were.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes, without a doubt. Yes. I work in a doctor's surgery at the moment and the different people that come in, and the problems that they've got, I think, without a doubt, any tool that's going to help towards providing a good quality of life for somebody, or a good quality of death, that's all part of it. I think anything that can help that would be so valuable.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I think because you've got a, something in front of you that you can look at, and, I mean, I know exactly where it is – I have put it away, but I know exactly where it is – and I think if, and when, because, I mean, I'm bound to have some problems at some stage or another. I keep saying and using the word "tool" but it's a tool for possibly the doctor or whatever, but it's also a tool for me because I can get that out, and I can look at it, and use it possibly to do a bit of self-analysis actually.

(Is it something you think you'd like to repeat at some stage?)

Yeah, I would. I think it would be very interesting to do that.

(And do you think it would be of value to other people as well, to do that type of thing?)

On an individual basis? Yes, I think it probably would – as I say, some people probably more than others, yes but I think it would be very interesting.

Other – you indicated in the final questionnaire you completed that you thought you would find it helpful in the future. Do you still think that's the case for you?

It depends what goes on in my life really. Possibly not three months but who knows what's around the corner, I mean something could happen, God forbid, and in that case yes, it would be helpful to re-analyse, re-evaluate where I'm at. And it's certainly really helpful to do that I think.

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Right, let me think. I think I looked at them one day, you know, looked at them one day for probably half an hour or so. And then I picked them up the next day, if I remember, and went through them then. Half an hour and then perhaps just over half an hour the second day.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

I did initially, and then, funnily enough, once you'd contacted me again I did.

(When you did initially, roughly for how long?)

It was mainly in the car when I was driving from one place to another, you know, and listening to the radio and what have you and something would perhaps twig a memory and I'd just say "oh I remember that". Ten minutes is probably about right.

(Was there anything in particular that you thought about?)

No not really, just things in general.

(So you were in the car and something would pop into your head?)

Yes, some music, or some comment or something.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No, I didn't afterwards, no.

Q4 Did you show the graphs to anyone?

No, well my wife saw them, because they were there on the table when she came home.

(Did you have a conversation about them?)

Only very briefly.

(Was it about anything in particular?)

Not really, just what it is it, kind of thing, have a look if you like – a general interest like.

(So did she say anything to you about them.?)

No, not really.

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No.

(Was there a particular reason why you chose not to discuss them with anyone?)

No, not really. I mean just it never came up, kind of thing. The subject never came up anywhere.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

No I don't think so.

(Is there any reason again why you would choose not to do that?)

No, I mean if anybody ever said "have you done this?" I'd say "oh yes, by all means".

Q7 Was there anything at all that you did as a result of looking at the graphs?

No.

Q8 What could we have provided that might have helped you to better use the information you were given?

Nothing I don't think.

(Prompt re phone call)

I mean, yeah, if you'd have called and raised the subject, I'd have thought about it.

(Prompt, re instruction leaflet, action plan, advice from doctor or HP, would that have made a difference do you think?)

Yes, probably.

(Which of those would have made the most difference for you?)

Well, you always listen to your doctor don't you, maybe that.

Q9 Do you think QoL information would be useful to share with a Health Professional?

Well, it wouldn't do any harm, definitely not.

(What do you think the value of it would be?)

Well, he might be able to read something into, umm, say I went along to see him with a problem, and he had that information there, he might be able to use it, you know, to assist in making the decision on what the problem might be.

Q10 What would you want a Health Professional to do with that information?

Well just hold it really.

(Would you want him to use that information in terms of helping you decide treatment plans or ...)

Yes, definitely. I think that's probably the biggest area that he could use it.

(And what about for yourself, if you were to discuss that information with your doctor, about how the two of you could use it jointly, would you want to use that information?)

Yes, I don't see why not.

(And what would you want to do with it personally?)

I think, maybe, if there's ever, kind of, any personal problem or bereavement or something or, not psychology or something like that, but something that, you know, could get into your mind somehow, I don't know.

(Would it be something you would use on a routine basis or would it be something you would think would be more appropriate if something exceptional happened?)

Yes, not routine.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes, I think so.

(Prompt – reminder of breadth of domains)

Yes, it's something that you could have and keep in file, keep on record for each individual.

(And the value of that would be?...)

That, I think probably, before he met his patient, he would have some understanding of the patient anyway. Or then, it wouldn't do any harm to have that. I mean, I remember, last year, my doctor who I'd had for years, and years, and years, he'd left and emigrated to South Africa. I got a new doctor, and now it's taken, well I see him twice a year, just for the MOT like, you know, and it's taken this long just to get an understanding with him, with the new one, you know what I mean? e started off by saying "what's your background, where do you come from etc. etc., what's your interests?" whereas if he'd have had all the information prior to that, could have read it, he'd have had some understanding, wouldn't he? These doctors' time now is so short and they're so busy all the time aren't they? Why wait half an hour or whatever getting to know somebody when you could get to know them before you met them.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I think as regards myself, it's not made any difference at all really, you know, I mean, it's something I did, and I enjoyed doing, that's it really. I don't know if anybody else, I can't think how they could do anything different you know, only it might make them think a bit more.

You said in one of questionnaires that it was somewhat helpful at the time you completed it. Would you still say that's the case?

Yes, it was [helpful] because it made me think... about me. Luckily my health's good and everything but you think "hmm what if not?" Before I did it I wouldn't have even thought that way. And [it's a way of] looking at yourself and saying "Yes, I'm okay, the way my life's being going is the right way". Whereas if there were certain things I could have said "ah, I'd better change this a bit, I've got something wrong here" you know. At least it made me think and realise I was okay, you know what I mean? If I hadn't have done it, then I'd never have thought that way and I have just carried on doing what I was doing, as it has I have carried on doing what I was doing because in my mind it was the right way to go.

P77 [14]

Monday 4th July, 2011 12.02 pm – 12.17 pm

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Only during the feedback conversation.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

I only thought about what the other one would turn out like. I know you don't send it out but I'd be interested to see what's come back out of it.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No, but I've still got mine upstairs, all the envelopes. I've tucked them away, up in the office.

Q4 Did you show the graphs to anyone?

No.

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

No, only my dogs!

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

No, not really, because I don't think anybody would be interested in it. I'm always interested in things like this but other people I don't think would be interested in what I'm interested in.

(That's absolutely fine, that's right and for other people they want to share it..)

I'm old fashioned.

(But there's no right nor wrong of it, it's entirely personal.)

Q7 Was there anything at all that you did as a result of looking at the graphs?

No.

Q8 What could we have provided that might have helped you to better use the information you were given?

I don't think so, I think you'd done all you could really.

(Prompt)

I don't think so. I think, umm, the only thing I would say, would, I mean, I know it's difficult what you're going to say, but I would have liked to have had feedback on the other one. That's the only criticism I've got, other than that I'm happy.

Q9 Do you think QoL information would be useful to share with a Health Professional?

Oh, every time I should think.

(Why?)

Well because it gives you probably more information that he doesn't know about.

Q10 What would you want a Health Professional to do with that information? Well I should think it wouldn't help me but it would help other people. I'm getting too old now.

(In terms of you personally, if they had that bigger picture of you, do you think that would help them in terms of the way they treat you or the advice that you're given?)

I don't know. I wouldn't say yes, I wouldn't say no, because at the moment they are very very good there. I mean I couldn't fault the service we get there at the moment.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

Yes, I think so, because I've got a friend and he's got to book a fortnight [in advance] to see a doctor or whoever, and I think that's disgusting.

(Do you think it would help people generally if, when they went, they had some quality of life information they could then discuss with their doctor?)

Yes, I do, yes.

(And what do you think the benefit of that would be?)

Well I think possibly knowing a bit more about the patient, their general [physical] health.

(What about the other aspects of quality of life, would those be useful for them to know about do you think?)

I should say so, yes. In general, I mean I think all over everything would be useful. But it's just getting the right balance. Not the amount of information but the sort of information, it's getting the right information I think.

(And is the sort of tool we used in the study appropriate?)

I thought what you're doing is a good thing. It was very good. It's going to help a lot of folk, you know, as I look at it.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

Probably, at the present moment, it probably couldn't do [much] because, you know, the doctor, he's done all what (sic) he really could do. I mean, possibly, I could say, in the future, for anybody else, I think yes, it could be, it could help other people.

(In what ways?)

Well probably getting, knowing more, about, like, what happened to me, it probably, they could probably store that and it would save a lot of hard work, but whether that would work I don't know.

You said on the very last form you completed ... that your experience of the study would be very helpful to you. Do you still feel that's the case, and if so, why?

Yes I think so. Well not especially for me, I think for everybody. I think it will help everybody. By going back to all the questions it would help everybody in the future.

(So do you think it was the asking and answering of the questions that's helpful or do you think it's getting the graphs back that's helpful?)

I think possibly it's getting the graphs back and knowing what there is there.

Other

If it helps anybody else, all well and good. That's the way I look at it – if it's going to help somebody else as well as me then that's the thing. I think possibly the doctors want as much knowledge as they've got. I must admit, at the moment we've got quite super doctors up where we are. I must admit they're very very good.

P6088176 [15] Tuesday 5th July, 2011 4.01pm – 4.15 pm

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Probably about half an hour

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

No.

Q3 Did you look at the graphs again after you had finished taking part in the study?

No.

Q4 Did you show the graphs to anyone?

No.

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

Briefly yes.

(And who did you discuss them with?)

With my husband.

(Are you able to tell me what you said to him and what he said to you?)

No. It's not that is personal, I just can't remember.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

No.

(Is there any reason why you would choose not to do that?)

No, no particular reason. Possibly, they wouldn't be interested.

Q7 Was there anything at all that you did as a result of looking at the graphs?

Not really no. Thinking maybe.

(In what respect?)

Whether I felt I'd answered it correctly I think.

(So in your case it was thinking about whether you'd completed the process?)

Yes, rather than changing my life shall we say (laughs).

Q8 What could we have provided that might have helped you to better use the information you were given?

No, I don't think so.

(Prompt)

Not really, not with my particular case I don't think, no.

Q9 Do you think QoL information would be useful to share with a Health Professional?

No, not really, well, I'm seeing a Health Professional anyway, fairly regularly at the moment.

(And would you share with that Health Professional the sort of information you had in the graphs – (recap domains)?)

No, probably not, no, more the physical.

(And do you think sharing actually that wider information would be useful?)

Yes, possibly. Yes, I think it would be useful but I can't see there ever being enough time for the Health Professional. I think you go and see your Health Professional and it's really physical what's wrong with you today sort of things rather than how you are emotionally. I think that rarely comes up maybe it [the graphs] would be a trigger for that.

(And you think discussing that wider picture would be helpful?)

I don't know, I really don't know. On some days I would say yes, on some days I would say no I don't want to discuss it. You have up and down days don't you? On some days I can really talk to someone on other days I don't.

Q10 What would you want a Health Professional to do with that information?

I guess to have a better understanding of me. Whether it went any further than that, I don't feel I've got major problems so, maybe if I had, I don't know. It's a difficult one really.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

If it's a yes and no answer, I'd say yes. Purely because I think they'd have a better understanding of that person.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

I really don't know. I think it can help make a difference because it makes you face it. You don't sit down normally every day and think about the things that are on that graph. So maybe it just focuses you.

(Prompt: reminder of QoL-importance gaps)

On a general point of view I think that could help an individual. It would focus their mind on "oh, look what I answered there" and it's quite a clear way of viewing the gaps. But I looked at mine and thought "oh, actually mine's not too bad!"

(So I'm getting the impression that you feel if there were bigger gaps it would be more valuable?)

Yes. I think it would focus the mind on why are those gaps there?

(Would it be something that you feel it would be useful to repeat periodically?)

Possibly, yeah, because I think where the questions, if I remember correctly were asked on how you feel now weren't they? I think you would probably get different results [if it were repeated]. It must be how you're feeling at that time.

(And you think it might be useful?)

I don't know because I think you can over-analyse things. I've had somebody die for example, in our family, since I did that [the study] so my views on certain things might change because of that, but then as you get through the grieving process you change again don't you? So I don't know whether it would be useful or not because I think you go through your life changing all the time, so I don't know. I just don't know, because you can go to the depths when something like that happens and if you happen to be filling it in that week, it would give masses of difference to how you answer and your results. Sometimes I think you can over-analyse things and with something like grief you just have to go through it. So you may look terribly on your chart if you answer those questions within those two weeks but then you'd expect it to. It's how you're feeling at the time, the highs and lows of life.

(Other comments?)

Not really no. I found it quite interesting but I must admit I haven't thought about it much since I did it.

P74 [16]

Monday 8th August, 2011

9.50 am – 10.06 am

Q1 Approximately how long, in total, did you spend looking at the graphs before you completed the second set of questionnaires?

Um..well..I'm quite a thorough person, um, you usually look at them when, as they're sent to me and then I put them down and then I usually reply the next day. It gives me thoughts to answer what.. yes.

(Ok, so we how long do you think you might have spent looking at them, because we talked about them when we were on the phone, and then did you have another look at them after that?)

Yes I did. Yes absolutely I did.

(For probably about how long do you think?)

Oh, I would think about half an hour I would think, to go through.

Q2 Have you thought about the QoL feedback with the graphs since you took part in the study?

Well yes, um, indeed I have because I was hoping, you know, I'd learn from that and help me with my lifestyle.

(Was there anything in particular that you thought about or was it just reflecting generally back on them?)

Well, just reflecting back on the different issues and hopefully, you know, um I can improve on that.

(And was there anything in particular that prompted you to think about them again, or was it just something you did spontaneously?)

Um, well no, as one does in life, you reflect on things. I did think back on it, yes.

Q3 Did you look at the graphs again after you had finished taking part in the study?

Yes, once more. I did, yes.

(And roughly when was that?)

Well, I have a folder and I put them away um. Well soon after we spoke on your conversation on the phone.

(So within a couple of weeks or so?)

Yes, very much so.

(And was there any particular reason why you looked back at them again?)

Well, just to check up that I, you know, what shall I say..., said the correct answers my best of ability. I'm always a bit worried about forms and I always sort of look back to see I, hopefully, you know, it's alright.

(Well, as I say, there's no right or wrong answers)

No, so I shouldn't have worried really.

(And did you look at any particular aspects of the graphs?)

Um, well, more my health side of it I did, yes.

(In terms of physical health?)

Yes, indeed.

(And what were you concerned about there?)

Well, um, you know, after having a heart attack, you know, you do reflect on things, you know (laughs).

(Ok, so that's what brought that into focus really?)

It really did, yes, very much so.

(And did you have any new thoughts about it when you then went back and looked at the graphs again?)

Um, no, that I was pleased with what I said and, you know, hopefully all goes well (laughs).

Q4 Did you show the graphs to anyone?

No-one at all. No-one knows anything at all because I thought it was confidential between you and me.

(Ok, no that's absolutely fine. You didn't and that's because you felt it was personal to you.)

Q5 Did you discuss the information in the graphs with anyone else (i.e. without actually showing them)?

Well, only my cousin and his wife. I said that I'd had a survey to complete but that was all.

Q6 Who (else) would you want to show the graphs to, or discuss them with, if you could?

Well I suppose my doctor, if my health, you know, wasn't so well. Yes, I would have discussed it with him, definitely.

(So for you, what would have you to do it spontaneously would be if you were in more poorly health?)

Yes indeed. Touch wood I'm doing very very well, so it hasn't cropped up yet.

Q7 Was there anything at all that you did as a result of looking at the graphs?

No, I don't think so. I live a very simple life anyway so, no, I think I'm doing exactly the same as I did pre the graphs, yes.

Q8 What could we have provided that might have helped you to better use the information you were given?

I don't think so. I think your follow up after I completed your survey and we discussed it. No I was quite happy, you know, there were no other further questions for me to ask you.

(So do you think me telephoning you to talk about was helpful?)

Well, yes, it was more personally wasn't it, you know, because it's out of the blue and then suddenly you get this graph, you know, survey to do, and talking personally to you, yes it certainly made it much easier to digest.

(Do you think it would have been different for you had you not had that phone call?)

Yes, I do. Yes. It helped because you can help me pick up on certain items that perhaps I wouldn't have been aware of. That was important.

Q9 Do you think QoL information would be useful to share with a Health Professional?

Well I would have thought so because when you go for an appointment, I mean it's only a few minutes to discuss a whole thing but when you've spent a long time over completing a survey like that, if they just scan through it, it would help them I'm sure it would.

(In what ways do you think it would help them?)

Well a) your lifestyle and, you know, there must be pointers there. I mean, you're professional people and they would pick that up, I'm sure they would.

(So it's really about being able to focus then perhaps on specific things that pop out?)

That's right, exactly.

Q10 What would you want a Health Professional to do with that information?

Obviously if any there's a diagnosis of anything you had, it would help, because your lifestyle is important. How you live is to your health really. And that's where I think the doctor would come into that equation.

Q11 Do you think Health Professionals should be made more aware of how their patients see their QoL?

I do. I think it's very important because, I mean, I'm very privileged to live in a lovely environment. But anyone else that has difficulty in housing or anything, I'm sure it reflects on their health, and, you know, it makes a lot of difference. I'm a very lucky person! And I appreciate it too!

(One thought that's cropped up, we've talked about doctors understanding your QoL, what about other health professionals like practice nurses or people in specialist clinics?)

Well, up to now, I don't have any, like, the nurses come to me at all. But in later life when you need more help I'm sure it would be very helpful because it's the personal contact isn't it, and it's reassuring when people come. I do Village Link, for instance, and I can see, people who have no transport and very few friends, how important it is, you know, personal contact. In that view, I can see, in later life, if you were in the same position, how important it would be to you.

Q12 How do you think QoL feedback, like the graphs you were given, could make a positive difference to you? / to others?

Well, how can I say? It would do because, you know, it's pointing out all the things. I mean, in life one just factors on a few things at a time. But with a graph like that, with a whole survey, it's portraying lots of different aspects of your life and how it changes doesn't it? Yes, I do think it would be important.

(And have you got any ideas or comments for us about ways we could improve the type of process, that would make it even more effective?)

Well, I do think your phone conversations have been important because it, as I say, going back to the personal thing, it does, when it's sent off in the post it's gone and finished isn't it? And when you get a feedback and you ask different questions it stimulates your brain and thinking how you constructed the survey. I certainly think how you've done it, if you have other people you survey and you don't phone, in my estimation it's important to have that contact.
